

Communicating Risk in Environmental Health: *A Case Study of Lyme Disease in Addison County, Vermont*

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I. Background

For most individuals, climate change typically conjures up notions of receding glaciers and stranded polar bears. However, it is reasonable to assume that most people will not see either one of these during their lifetimes. This notion creates an inability to accurately assess the physical and temporal proximity of environmental issues and demonstrates why so many individuals fail to classify climate change as a pressing matter. Furthermore, endless disputes over the existence, agents, solutions, and significance of climate change all contribute to a lack of collective action.

On the other hand, suppose that climate change were framed in a way that focused on an increased threat to our health, whether in the form of an infectious disease, a mental health concern, an increase in childhood asthma, or heat stroke. Environmental health risks have immediate physical consequences across population groups. Might framing climate change as an issue related to public health resonate with a broader and more diverse proportion of Americans who may not otherwise care about environmental issues?

Environmental health considers all public health related issues affected by the natural and built environment. These issues include heat stress, vector-borne diseases and blue green algal blooms, to name a few. As the climate continues to get warmer, such environmental health issues will pose greater risk. For example, in the case of vector-borne diseases such as Eastern Equine Encephalitis (EEE), Lyme disease and West Nile virus, warmer temperatures and increased moisture may open up previously uninhabitable territory for vectors, increase reproductive biting rates, and shorten the pathogen incubation period (Brownstein et al. 2005, 39). The result is a redistribution of vectors to more places and for longer periods of the year. The United States is already seeing the consequences of these changes to public health. According to the Centers for Disease Control and Prevention (CDC), the average number of reported cases of Lyme disease in 2013 was 600% higher than it was seven years earlier (CDC 2014). This change is especially visible in the New England region. In Vermont alone, there has been a substantial acceleration in Lyme incidence as the number of confirmed cases per 100,000 people rose from 8 in 2004 to 108 in 2013 (CDC, 2013). Despite an ongoing controversy surrounding the diagnosis and precise medical definitions of Lyme disease, the nearly threefold increase in reported cases over the past two decades in the U.S. as well as the expanding geographic range of these cases indicate that Lyme disease is indeed spreading (CDC, 2013). As this example of vector-borne diseases

demonstrates, the effects of climate change on environmental health are steadily increasing.

Given the mounting scientific evidence that climate change and human health are inextricably linked, as well as the growing recognition of climate change as a health threat from organizations such as the American Medical Association, communication around these two topics is becoming increasingly relevant (JAMA, 2014). Communication on climate change and public health is important to protect humans from environmental health risks and engage more people in climate change mitigation and adaptation strategies. The current discourse on climate change in the United States has a polarizing effect on creating meaningful and progressive dialogue on the topic. However, framing global warming as an issue pertaining to public health focuses on the immediate implications that a warmer climate could have on people's lives and may have the capability of producing more emotionally compelling responses among individuals (Myers et al. 2012). This strategy also has the advantage of providing a sense of hope that the problems can be addressed and avoided, if people take action early enough. Additionally, the avenue of public health has the benefit of possibly remediating the fatalistic mindset surrounding climate change that many individuals hold by providing them with the sense that they can become part of the solution to the problem. Therefore, communication that draws connections between climate change and public health has the potential to protect against increasing environmental health risks and engage more people in the discussion around climate change.

Accordingly, the CDC has developed tools such as the Building Resilience Against Climate Effects (BRACE) framework to help state health departments understand how climate has and will affect human health and enables them to employ a systematic, evidence based process to tailor their responses to local circumstances (CDC, 2014). In conjunction with this large national effort, the Vermont Department of Health (VDH) recently won a four-year, \$1 million grant from the CDC to identify the most pressing health threats posed by climate change and to develop strategies for lessening their impacts. The Middlebury College students conducting this study have been working in partnership with David Grass, Environmental Health Surveillance Chief at the Vermont Department of Health. Our main goals are to assess the extent to which adaptive behavioral changes are actually occurring in the state of Vermont, and to identify whether and how individuals use the knowledge they gain from different forms of public health information to make these changes. This study also aims to present the VDH with recommendations by evaluating how public health information pertaining to vector-borne

diseases is reaching different population groups across the state, affording the VDH with the ability to communicate more effectively with specific communities.

II. Focus: Vector-borne Diseases in Vermont

We chose to focus our work on vector-borne diseases, as they are public health risks that are particularly relevant in Vermont. Vector-borne diseases are bacterial or viral illnesses transmitted by mosquitoes, ticks, and fleas. Mosquitoes in Vermont have the potential to carry West Nile virus or Eastern Equine Encephalitis (EEE). West Nile virus was first detected in Vermont in 2000 and a few cases of illness are reported each year in people and animals. However, the spread of West Nile virus is, at this point, quite limited and the risk to humans is relatively low. As with West Nile virus, EEE has thus far been relatively rare in Vermont. EEE is transmitted among wild birds by mosquitoes that do not usually bite humans. While cases tend to be rare, the impacts are high, with an approximately 30% fatality rate. Additionally, neurological damage is common among those who survive (Gubler et al., 2001). EEE has also garnered attention following two deaths from the disease in Rutland, Vermont in September of 2012 (Addison Independent, 2012). Both of these mosquito-borne diseases are relevant to current public health awareness in Vermont.

Ticks are another vector of public health concern in Vermont. Of the thirteen tick species found in Vermont, only four are known as possible vectors for human diseases. The diseases they are known to carry are Lyme disease, Anaplasmosis, Babesiosis, Rocky Mountain Spotted Fever, Tularemia, Ehrlichiosis, and Powassan (VDH). Of these diseases, all but Lyme have mild symptoms, are uncommon, and/or have never been reported in Vermont. Lyme disease is of particular interest because the increase in number of cases reported to the Vermont Department of Health has accelerated since 2005. The VDH has not reported on any diseases carried by fleas that were of public health concern in Vermont. Therefore, we chose to look at West Nile, EEE and Lyme disease as the most relevant vector-borne diseases in Vermont, and focused the majority of our research on Lyme disease.

The Role of Climate and Potential for Increased Risk

The Journal of the American Medical Association recently published a ground-breaking article focusing on climate change and the challenges and opportunities it poses to global health

(Patz et al., 2014). One of the risks to human health identified in this paper was the change in dynamics of vector-borne diseases. Changes in climate can influence the range, density, life cycle, reproductive rates, and likelihood of pathogen infection in several vectors known to spread diseases. It is crucial to understand the role of climate in human health risks and how it may play into the current and future risks for populations and regions. Once these risks are understood and communicated, mitigation and adaptation strategies can be implemented to help combat these issues in the face of a changing climate.

Vector-borne diseases and the risks they pose to human health are sensitive to changes in climate. Vector populations are controlled by density-dependent factors like competition, predation, and parasitism, but their geographic range is dictated by factors, such as climate, that influence habitat suitability (Brownstein et al., 2005). A changing climate could impact vector-borne diseases through three main channels: shifts in suitable habitat area, changes in survival, developmental and reproductive rates, and increased biting and infection of vectors (Patz et al., 2014).

Climate change is associated with changes in temperature and precipitation patterns, which can alter the range across which disease-bearing vectors can survive. The vector for Lyme disease is the black-legged tick (*Ixodes scapularis*). The survival rate of black-legged ticks (commonly called “deer ticks”), known vectors of Lyme disease, is largely dependent on factors such as water availability and temperature (Brownstein et al., 2005). As climate change alters temperature and precipitation patterns over an area, it may open up area that was previously unsuitable habitat for these ticks and allow them to expand their range. The expected range changes of black-legged ticks in response to climate change was modeled by researchers in the Department of Epidemiology and Public Health at the Yale School of Medicine. They found that redistribution of the Lyme vector will be one of expansion, particularly further north, with possible range contraction in its southernmost reaches (Brownstein et al., 2005). The life cycle of black-legged ticks is also dependent on climate related factors, which makes the species sensitive to climate change. These ticks require a long, warm spring-through-autumn period in which to complete their life cycle (Tuite et al., 2013). As minimum temperatures rise, the range supporting this temperature interval will push further north, allowing the ticks to successfully complete their life cycle in new regions. With increasing tick abundance, there will also likely be an increase in the pathogens they carry (Ogden et al., 2014). Thus, as black-legged tick ranges expand with

climate change, it is predicted that populations of the Lyme-causing pathogen will also increase and expand, leading to an increased risk for Lyme disease infection in humans.

Vermont has already seen a drastic increase in risk for Lyme disease since 2005, and stands to see further increases in risk. In general, the predicted trends for black-legged tick populations have been and will continue to be a pattern of expansion, especially in the north. One study found that the changes seen in vector-based invertebrate ranges as a result of climate change are occurring even more quickly than models have predicted, and that impacts may develop rapidly (Tuite et. al., 2013). Thus, it is especially important to effectively communicate Lyme disease risk so that people can take adaptive measures to this changing public health threat.

Lyme as a Focus Disease

We chose to focus on Lyme disease since it is one of the most prevalent diseases in both public experience and awareness; furthermore, its increased risk in Vermont is clearly tied to climate change. Since 2005, the number of cases of Lyme disease in Vermont has risen significantly, and in 2011 Vermont had the second highest rate of infection in the country at ten times the national average (CDC). However, it is important to note that the case definition used for the national reporting of Lyme disease had changed twice during this period of increase—once in 2008 and again in 2011. The changes in 2011 included small changes in the details of the criteria for laboratory diagnosis, with no changes to the clinical description or classification of Lyme cases (CDC 2008, 2011). These are minor clarifications that would not have large impacts on the number of diagnosed cases of Lyme. Nevertheless, we found that even if we were to discount the reported increase in Lyme cases, we could still easily provide sufficient evidence of increased risk to Vermonters when looking only at the range shifts of the Lyme disease vector—the black-legged tick—as a result of a changing climate. The risk for Lyme disease is widespread across subpopulations of Vermont, with cases reported in all counties and across all age groups (VDH). While EEE also held potential for high levels of public awareness due to the 2012 deaths, we decided not to use this disease as our focus because the two deaths happened close to our study area. We wanted to avoid the specific tragedy and be able to target a disease that many individuals have experienced in a more general way.

Because of its prevalence, Lyme disease served as the most pragmatic choice through which to engage with vector-borne diseases more widely. As of 2001, Lyme disease is the most

common vector-borne disease in the United States (Gubler et al., 2001). This prevalence gives us the best chance to engage in the emotional and other secondary effects associated with the disease, as more people will have encountered the disease in their lifetime than other vector-borne diseases. We believed that focusing on Lyme disease would increase public engagement in our project because people would be more likely to relate to it through a personal story or experience. Therefore, we could assess what the impact of such personal experience is in relation to communication of similar risks and adaptive behaviors in the future. For example, would individuals who have been personally affected by the disease—through their own illness, illness of a friend or family member, or the illness of a pet—be more likely to engage in preventative behaviors, have a higher perception of the risk, and be more aware of the risk for other vector-borne diseases? Through focusing on Lyme disease, we began to answer these types of questions and investigated ways to more effectively communicate about Lyme disease and other public health risks.

III. Risk Perception and Communication

In risk communication, public health officials must be keenly aware of neither overstating, nor understating, the particular risk in question to human health. Misperceived risk could result in potential physical or financial harms to individuals (Fischhoff et al., 1993, p.184). For example, in the case of Lyme disease, if individuals perceive the risk to be too high, those who earn their livelihoods outdoors may suffer financially; however, if individuals perceive the risk to be too low, they may increase their likelihood of contracting the disease. Therefore, the goal of communication is for the public to understand potential health threats and make the best health-related choices. A general understanding of human behavior is that if an individual perceives a high risk, he or she is more likely to take risk-averting action. However, the field of psychology suggests that humans are not always rational beings; factors such as biases, denial, and self-efficacy all contribute to individual decision-making (Schwarzer, 2001, p.48). A crucial task for public health officials is to understand how to best communicate a risk and how risk perception influences behavior change.

The relationship between risk perception and behavior change is influenced by a variety of social, emotional and cognitive factors. While perception of risk is an indicator of potential

behavior change, it cannot predict behavior change by itself (Schwarzer, 2001, p.2). One of the most influential theories of behavior change is the Social Cognitive Theory, which suggests that an individual is more likely to adopt a behavioral action through observation, especially if the behavioral action aligns with the individual's existing lifestyle (Fischhoff et al., 1993, p.194). Based on this theory, narratives can serve as a useful means of communicating information. Narratives provide a familiar way of receiving information that also encourages observational learning (Hinyard & Kreuter, 2006, p.6). The Social Cognitive Theory makes an assumption that an individual's intention is the best predictor of behavior change; however, individuals do not always follow their intentions (Schwarzer, 2008, p.2).

Another theory model predicts health behavior change on perceived self-efficacy rather than perceived risk. This theory, the Transtheoretical Model of Behavior Change, suggests that an individual's belief that they are able to change their behavior is an important determinant in predicting behavior change (Schwarzer, 2008, p.6). Alternative theories that model health-behavior change include the Precaution Adoption Process, the Theory of Reasoned Action, and the Adult Learning Theory. The Precaution Adoption Process suggests that individuals who know others concerned and changing their behavior are more likely to change their own behavior (Hinyard & Kreuter, 2006, p.7). The Theory of Reasoned Action is the "belief that others—even strangers—[who] approve of a behavior (normative beliefs) can influence a person's intent to engage in that behavior. This is especially true if the "others" are seen as important, valuable or credible," such as medical professionals (Hinyard & Kreuter, 2006, p.7). The Adult Learning Theory suggests that the most effective types of communication are those that build upon an individual's previous experience and therefore are more easily assimilated into one's mental model (Neuhauser & Paul, 2012, p.130). The various models of behavior change suggest that behavior change is quite difficult to predict. The models themselves, however, are useful in providing a variety of potentially effective tools to contribute to the field of public health communication.

Communication Theory	Factors Affecting Behavior Change
Social Cognitive Theory	Individuals learn through observation; Intention is indicator of behavior change
The Transtheoretical Model of Behavior Change	Individuals experience 5 main stages of change; Precontemplation, Contemplation, Preparation, Action, Maintenance. Emphasizes perceived self-efficacy as important determinant of stage change.
Precaution Adoption Process	Individuals who know others concerned and changing their behavior are more likely to change their own behavior
Theory of Reasoned Action	Individuals who believe that others approve of a behavior are more likely to change their behavior
Adult Learning Theory	Individuals are more likely to change behavior if it builds off of previous experience

Given the complexity of risk communication and behavior change, it is imperative that public health educators are effective in conveying information. The public's health literacy relies on the readability, comprehension and usability of information provided to them (Neuhauser & Paul, 2012, p.131). Health informational materials can often deter the public because of their emphasis on statistical information. Therefore, framing the information in ways that are accessible to a range of audiences is an important strategy.

The CDC states that some of the barriers to health literacy include "reliance on print communication, focusing on information rather than actions and limited awareness of cultural differences" (CDC, CDC Health Literacy for Public Health Professionals Training). Several ways to increase readability and accessibility of health communication include using simple language instead of medical jargon, tailoring communication materials to audience needs and preferences, and using participatory design where audiences can engage in personally relevant and actionable communication tools (Neuhauser & Paul, 2012, p.131). It is also important for health professionals to show both the risks and benefits of their health-related behaviors (Peters, 2012, p.93). Evaluating the effectiveness of health communication by measuring whether or not members of the public are changing their behavior is another important step in making better

communication materials. These techniques and evaluations of risk communication are tools that can be utilized in the larger context of climate change communication.

IV. Climate Change Communication

Despite the growing body of scientific evidence stating that climate change is happening and that humans are the primary drivers of this phenomenon, the general public is still largely divided about the question. Therefore, communicating the causes and consequences of climate change is a complex issue that needs to be dealt with delicately and through a variety of approaches. Using public health as a frame for climate change communication is a strategy that deviates from traditional environmental and economic framing mechanisms to engage the American public with climate-related issues.

Studies have shown that, contrary to instinct, more information does not necessarily lead to better understanding (Geiling, 2014). Therefore, we know that a better-informed public will not necessarily take the needed steps towards climate change mitigation. This is because individuals tend to filter information in a way that affirms their already-held beliefs. In other words, as mentioned earlier in reference to risk perception, cultural cognition strongly motivates people – of *all* worldviews – to recognize information as sound in a selective pattern that reinforces their cultural predispositions. This realization becomes especially relevant when considering communication around climate change, where there seems to be an especially large chasm between scientific knowledge and public understanding. Therefore, it is not enough to ensure that scientifically sound information is widely disseminated; communicators must attend to the cultural meaning of their messages.

One such approach is the use of locally framed messages. Studies have proven that personally relevant messages are more engaging and more persuasive than globally framed ones (Scannell et al., 2011). In our case, conceptualizing climate change in local terms, like the increased threat of Lyme disease to Vermont, may be more tangible than when presented in terms of global events such as rising sea levels, intensified droughts, or melting glaciers. This is exactly the strategy that our project employs, since the increased spread of vector-borne diseases is the most salient local manifestation of climate change to Vermont residents. In this way, we are hoping to not only help communication efforts around this specific issue, but also to foster

more conversation around the overall issue of climate change in these affected communities.

Another effective communication strategy is called identity affirmation. When people are presented with risk information (e.g. rising global temperatures) that they associate with a consequence that is threatening to their cultural values (e.g. global commerce must be constrained), individuals tend to react dismissively (Kahan et al., 2010). However, if the same information is shown with a positive consequence (e.g. more cohesion in local communities), they are more likely to consider accepting a possible paradigm shift in their beliefs and behaviors. This means that to convince more of the general public that climate change action is needed, policy-makers should highlight the positive consequences of mitigation measures instead of focusing on society-wide sacrifices.

Another technique for effective communication is called pluralistic advocacy. In order to persuade individuals from all walks of life, information about climate change needs to come from a variety of public figures. Individuals tend to discard information that is being advocated by experts or laypeople whose values they reject and vice versa (Kahan et al., 2011). This is why we have chosen to present information about Lyme disease from diverse perspectives including those of a medical professional, a scientific expert, and laypeople affected by Lyme. We are looking to ascertain whose message will resonate most with the public.

These theoretical pillars to effective climate change communication techniques have guided our design and analysis of communication methods around Lyme disease and its larger context, global climate change as well.

V. Methodology

Throughout our research, we utilized several different methods that spanned the qualitative-quantitative spectrum. Our overarching research goal was to gain insight into awareness, adaptive behaviors, risk perception, and communication surrounding vector-borne diseases in Vermont. When gathering initial data, we used quantitative survey methods such as checklists, frequency ratings, and yes-or-no questions. To account for the nuances in personal knowledge and acquire deeper perspectives, we employed qualitative methods to gather data through conducting interviews, holding focus groups, and asking open-ended survey questions. Generally, quantitative methods were applied to awareness, adaptive behaviors, and risk

perception, whereas qualitative methods were applied to communication research. It is important to note that the nature of our research is highly contextual; none of these issues can be approached in a purely quantitative or qualitative manner. Therefore, most of our methods do not fall squarely within one category or the other.

Our work is not intended to prove hypotheses in the style of rigorous scientific research; rather, we are looking to build upon the capacities of our research group as a team made up of students with a variety of skills and interests from different foci within the Environmental Studies Program at Middlebury College. Furthermore, although our research seeks out respondents' perceptions of the relationship between Lyme disease and climate change, we let such conversations occur organically and did not include active climate change discourse within our methods. It was not within the scope of our research to engage in debates about the connection between Lyme and climate change, nor would it have been efficient to derail conversations about Lyme awareness and communication with tangential climate change discourse.

Surveys

We used surveys as our initial method of data collection (see Appendix A). We posted an online version to Front Porch Forum, a town-based, online listserv, reaching users in Middlebury and eight surrounding towns. Responses from Front Porch Forum users comprise 157 of the 269 surveys collected. Because we wanted to reach out to populations who may not have internet access or may prefer not to use it, we distributed paper copies of our survey at the Middlebury Farmer's Market, HOPE, The Lodge at Otter Creek, Community Supper at the Congregational Church, and the Lake Champlain Waldorf School.

Our survey assessed baseline risk perceptions of vector-borne diseases (Lyme/EEE/West Nile), the channels through which respondents receive and access information about these diseases, and whether and how respondents were taking precautions against vector-borne diseases. Additionally, we identified the factors to which respondents attribute the increase in the statewide incidence of Lyme disease. Although we were seeking to gather data on whether or not respondents attribute this increase to climate change, we intentionally left out any mention of climate change from the survey, as we sought to engage respondents of all environmental and political persuasions. Climate change is entirely based in nonpartisan science; however, we

recognize that this topic continues to be controversial and aggressively politicized in this country. Therefore, it was most prudent to give respondents space to share their personal answers without disengaging respondents for whom climate change is tied up in political views and skepticism. Furthermore, asking this question in an open-ended format (e.g. *Why do you think this is?*) removed the possibility of bias in responses caused by a leading question (e.g. *Do you think that climate change is the cause of this increase?*).

We placed a brief, optional, demographic section at the end of the survey and collected basic information (income, gender, occupation) in order to identify patterns of awareness and action across different populations. Ultimately, collecting these data gave us the potential to target communication recommendations toward specific subpopulations. Placing the demographic information at the end of the survey, rather than at the beginning, was intentional in that we did not want to disengage respondents who might be uncomfortable with personal data collection. These respondents could just skip that information at the end and simply hand the completed survey in, rather than see demographic data collection at the beginning of the survey and quickly become skeptical of our intentions or discomfited by our approach.

Our goal was to collect data we could use for simple quantitative analyses. This dictated the survey format in that we offered respondents a pre-defined set of answers to choose from; consequently, we limited the need for pre-analysis coding. Furthermore, the format of the survey allowed us, as researchers seeking consistent data, to pose the same questions in an identical format 269 times and eliminate the potential for variation in question delivery.

Although the survey tool was practical and efficient for reasons outlined above, the way in which we went about creating the survey presented some limitations. First, in the interest of saving time, we did not test the survey before distributing it. Although we proofread the questions, we might have caught some contradictions, confusing phrasings, or issues with formatting if we had recruited a test set of respondents to complete the survey and suggest edits. See Appendix A.1 for question-by-question limitations of the survey that we learned about from respondents. We also never assessed the literacy level of the survey. Since a goal of our methodology is to reach diverse populations, including those who may have a lower level of literacy, assessing the readability of the survey would have been an important first step. With the added confidence that respondents, beyond a doubt, understood the questions that they answered, we would have had greater confidence in our results. Using the Suitability of Assessment of

Materials (SAM) index, our survey received a rating of 61%, placing it in the category of “adequate,” but not “suitable,” material (see Appendix A.2) (Neuhauser, 2012). The SAM index is a tool that is used to systematically and objectively assess the suitability of written health information. Although this survey is not the intended application for the index—given that its format is more interactive and response-based—the SAM index is adaptable to different material and remains a useful assessment tool.

Verbal Surveys

Using brief verbal surveys, we collected information on the relative impacts of various methods of visual data representation. Inspired by the work of Severtson and Vatovec (2012) on map-based representations of environmental health risks, we sought to produce recommendations for communication materials that clearly impart risk and an appropriate sense of urgency upon viewers. Specifically, our goal was to assess the potential that particular graphical features, scales of geographical representation, and frames of risk portrayal held to engage viewers in understanding their risk for Lyme disease.

We accumulated 18 responses from Middlebury Natural Foods Co-Op shoppers, 6 responses from the Addison Central Teen Center, 7 responses from Hannaford Career Center students and 11 responses from the Middlebury College Community. Verbal surveys, in which we asked respondents questions as they were looking at the maps and recorded their answers, were an appropriate method given our research goals and surveying locations (see Appendix B). We had specific research questions, but were looking for personal answers and reasoning. If our research had been conducted only by paper survey, respondents would have had to write short narratives while juggling groceries and tight schedules, whereas this method allowed for concise conversation that left respondents with free hands and less of a time burden as they agreed to answer a few questions.

We presented respondents with five different geographical representations of Lyme disease risk that were gathered from various public health sources (see Appendix B, Maps 1-5). We displayed four maps that showed Lyme disease risk on increasing scales, ranging from a map showing individual tick reports in Vermont to a heat map of risk level for the entire Eastern United States. These maps also vary in their use of color scheme and level of aggregation of data. After respondents compared these four maps through a series of verbal survey questions,

we presented a graphic that showed the change over time in Lyme incidence. Here, we sought to assess the power of including this change over time component in communication, hypothesizing that it would increase and/or reaffirm respondents' perception of risk.

For the same reasons that we excluded mention of climate change from the initial electronic survey, we excluded it from our verbal surveys so as not to detract from respondent engagement. Furthermore, climate change is unrelated to the goal of identifying strengths and weaknesses of these particular data representations. However, when asked about the change over time graphic, many people made the connection between the northward migration of Lyme over the past 15 years with the same geographic shift in precipitation and temperature.

Again, a strength of this method is that respondents were able to spontaneously participate in our research and we were able to efficiently gather rich data in conversations that usually lasted about two minutes. Furthermore, the conversational delivery of our survey encouraged respondents to provide natural, intuitive responses without being distracted by the presentation of the survey or pressure to fill it out. While having these discussions, we were able to unobtrusively record respondents' answers in a systematic manner. In this way, we capitalized on the efficiency and clarity of quantitative methods while engaging with respondents in the manner of more qualitative investigation.

Focus Groups

In the second phase of our research, we collected data about the framing of Lyme disease communication through a series of focus groups. We chose to focus on framing because the different ways in which the same material is communicated can change the meaning of the material for viewers. Depending on which frame, or perspective, viewers are most engaged with and responsive to, they are more or less likely to retain and act on the information that is provided. As we sought to formulate recommendations about Lyme disease communication for the VDH, the issue of framing became just as important as the question of content. We found that even if the content is engaging and of high quality, it is not effective if viewers do not trust the source of information and relate to its narrative perspective.

We emailed an appeal for participation to 54 individuals who provided their contact information at the end of the initial electronic survey, and also posted a copy of the appeal on Front Porch Forum for Middlebury and eight surrounding communities. We conducted five focus

groups comprised of twenty-five total participants at Carol's Hungry Mind Café in Middlebury, chosen for its neutral, downtown location and widespread appeal. Focus group discussions ranged in length but most lasted about forty-five minutes, and each discussion was run in a consistent manner.

First, we concisely explained the goals of our research and how this discussion on framing and communication fit into the larger picture of our work. At this point, we also emphasized that we were more interested in the larger issues of (1) how framing informs risk perception and (2) identifying effective communication elements rather than in discussing the merit of the communication materials' content. Then, we presented three two-minute video clips with different narrative frames: personal testimony of individuals with Lyme disease, a doctor's perspective on the risks of Lyme, and a biologist's narrative about Lyme risk and prevention in Vermont (see Appendix C). We delivered the videos sequentially with time for reflection and evaluation in between. After watching all three videos, we asked participants to fill out a short survey in order to supplement our qualitative observations with quantitative data (see Appendix C).

In the interest of time, we chose to use pre-produced videos rather than create our own work. We identified what frames we wanted and then found videos on YouTube to fit these frames. A limitation of this choice was that we might have overlooked stronger Lyme narratives because they did not fit into a medical, scientific, or personal story frame. To choose the three video clips, we identified that each originated from an authoritative source and emphasized its narrator and his or her perspective as much as possible.

The strengths of the focus group method lay in its potential to gather rich data about framing and elements of communication from a small sample size of participants. Furthermore, we could identify more nuanced thoughts and probe more deeply into participant opinion through open-ended discussion-style facilitation. Given this format, we anticipated that there would be challenges with guiding participants to stay on topic and not become sidetracked by stories of personal medical issues and frustrations having to do with the pervasive debate about the existence of "chronic Lyme" disease. Through explaining our research goals at the beginning and pointedly phrasing discussion questions (*Which elements of the video caught your attention?* vs. *What did you think about the video?*), we were able to make the most efficient use of our time and access to participant feedback. While our approach was intentionally focused on the

effectiveness of communication styles, we intentionally did not stifle personal stories or experiences when those arose out of our conversations. We recognized, rather, that storytelling was an important part of the discussion process for participants and that it also provided a context of urgency for our communication research. Our impression was that the majority of our discussion group participants had Lyme disease at some point or had someone close to them with the disease, meaning that all participants were personally affected by the disease. Therefore, this sample of the population was not completely representative of the general public; however, this limitation does not diminish the value of the responses we got from our participants.

Interviews

We conducted informal interviews over the course of the entire project with the goal of expanding our research perspective and reinforcing data collection through the power of individual narratives.

Through conducting interviews, we accessed a deeper level of personal opinion than was possible through other methods. We were able to focus on one individual at a time, and ask questions specific to his or her knowledge, experience, and style of communication. When we made it clear that we wanted a personal assessment of an issue or problem, the interviewee generally opened up and helped to create an organic, flowing, conversation. One limitation of the individual interview is that interviewees were unsure about the risk perception and preventative measures that others were taking in the community; they were predictably more eager to speak to their own experiences. While we do not discuss them further in this report, these interviews complemented and informed our other methods.

Subject Selection

In selecting our research subjects, we made no attempt to thoroughly represent a specific population or the demographics of Vermont as an entire state; furthermore, this was outside the scope of what was achievable in one semester of work. However, we were looking for patterns that may be useful or important in further study of communication surrounding vector-borne disease. Given that vector-borne disease does not discriminate, it was appropriate to identify the subpopulations present within Addison County and make a reasonable effort to engage representatives from as many of these communities as possible. Examples of identified

subpopulations included: religious organizations, low-income individuals, students, farmers, people with a personal connection to Lyme disease/EEE/West Nile, elderly residents, outdoors people, parents, and those without internet access. See Appendix A.3 for a demographic breakdown of our electronic survey results based on income, age, and gender.

VI. Results

Written Survey Results

A total of 269 people filled out our survey on vector-borne diseases in Vermont. Of the respondents, 98.5% had heard of Lyme disease. Fewer people had heard about Eastern Equine Encephalitis (84.4%) and West Nile virus (90%). *It is important to note that the majority of survey participants were aware about the existence of these diseases, indicating that this issue is prevalent in the community.*

Awareness of Vector-Borne Diseases

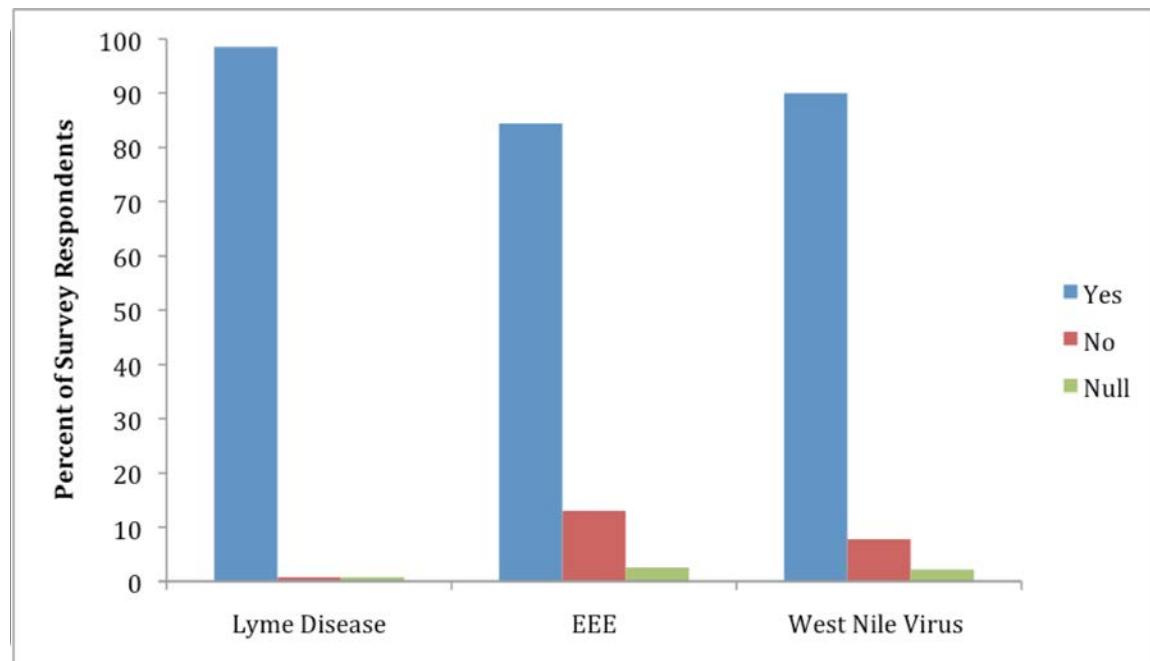


Figure 1: Percent of survey respondents that answered Yes or No to the question of whether they had heard of Lyme disease, Eastern Equine Encephalitis, and West Nile Virus. This graph corresponds to question 1 in the survey.

Our survey looked at the number of people who knew someone (including themselves) who had contracted one of these vector-borne diseases. Of the people surveyed, 69.8% knew someone with Lyme disease. More people knew someone who had Lyme disease than EEE (1.8%) or West Nile Virus (1.1%). *This shows that Lyme disease was much more salient to our respondents, validating our reasons for focusing on this particular disease.*

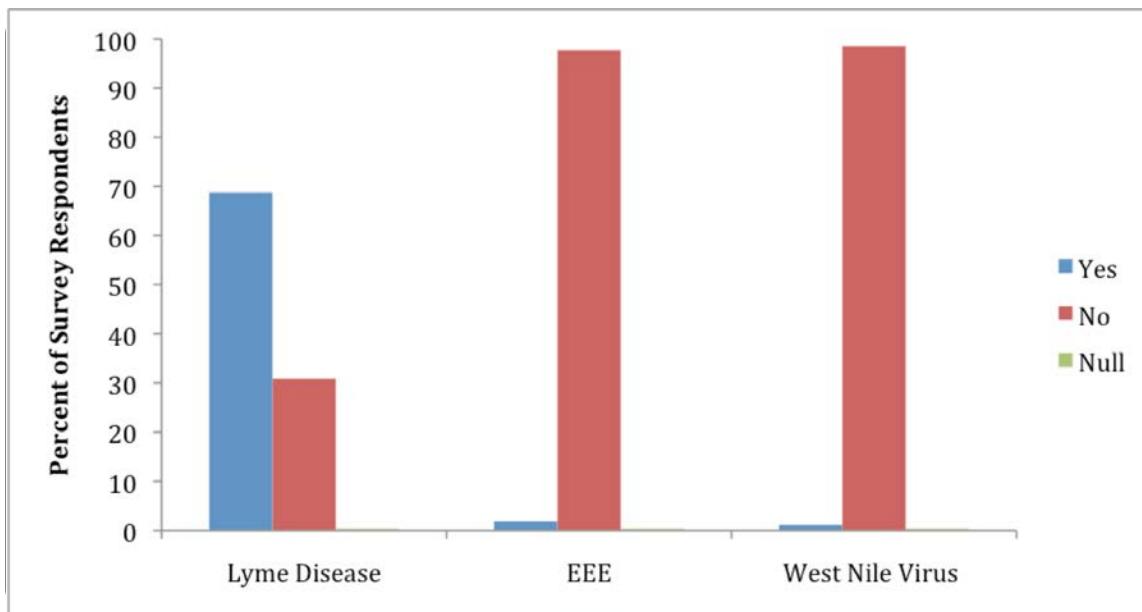


Figure 2: Percent of survey respondents who circled that they either knew someone with Lyme disease, Eastern Equine Encephalitis or West Nile Virus *or* had personally experienced these diseases. This graph corresponds to question 2 in the survey.

Risk Perception

To examine perceived risk, we asked how likely the participant thought it was that he or she would get one of the diseases (Figure 3). The type of disease was not specified. The idea behind this question was to connect it to question #2 in order to examine whether knowing someone, or personally experiencing the illness, impacted a respondent's perceived risk of contracting the disease. Of the total respondents, 58.7% thought it was moderately likely that they would contract a vector-borne disease. This is an important finding because it shows that more than half of our respondents were aware that they are moderately at risk for contracting a vector-borne illness. A similar number of people either didn't know the likelihood (13.7%) or thought it was not at all likely (9.29%). A total of 17.8% of people thought it was very likely that they would contract a vector-borne illness. Combining the percentages from those who thought they had a moderate risk with those who thought the risk was very likely, *we found that 76.5%, or more than three-quarters, of our respondents feel they are at risk for contracting the diseases.* This is a high percentage of our survey respondents, showing that many people feel they are at risk and that awareness of these diseases has penetrated the community.

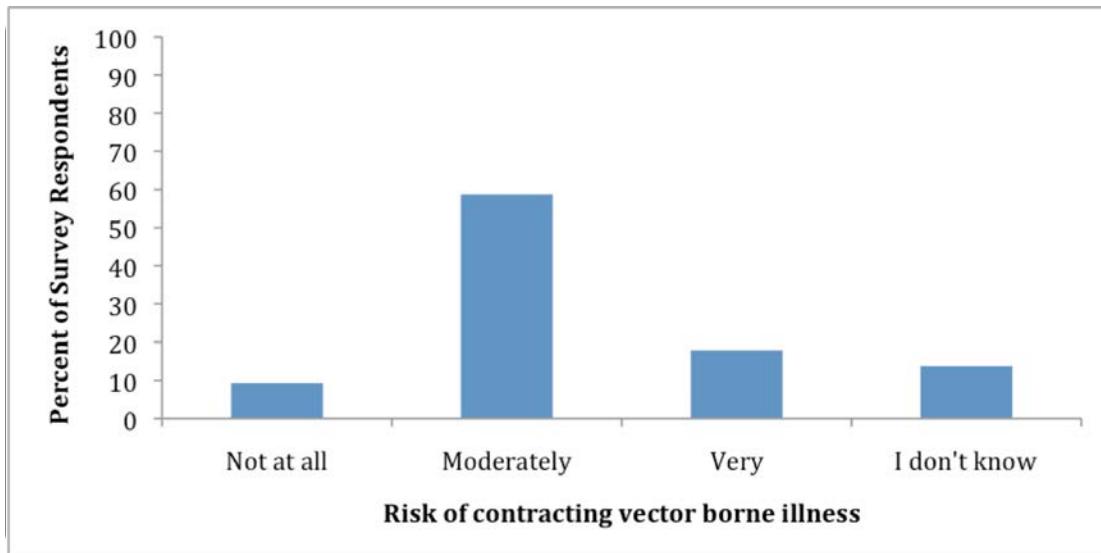


Figure 3: Respondents' perceived likelihood of contracting a vector-borne illness.

Perceived risk and personal connection to disease:

We wanted to examine how a person's perceived likelihood of contracting a vector-borne illness correlates with whether they knew someone who had the disease. This is a compelling relationship to investigate because it looks at how personal connection with a disease impacts risk perception (Figure 4). Of the respondents who thought it was not at all likely that they would contract a vector-borne illness, 45.8% knew someone with Lyme disease. Of the respondents who thought it was moderately likely, 71.3% knew someone with Lyme disease. Of those that thought it was very likely, 85.4% knew someone. *This information indicates that knowing someone with Lyme disease could have a significant impact on a person's risk perception of contracting the disease.* We found no clear trend between knowing someone with EEE or West Nile Virus and the perceived likelihood of getting a vector-borne illness, but the lack of such a finding may be because of a more general lack of awareness, or lack of concern about EEE and WNV relative to general awareness of and concerns about Lyme.

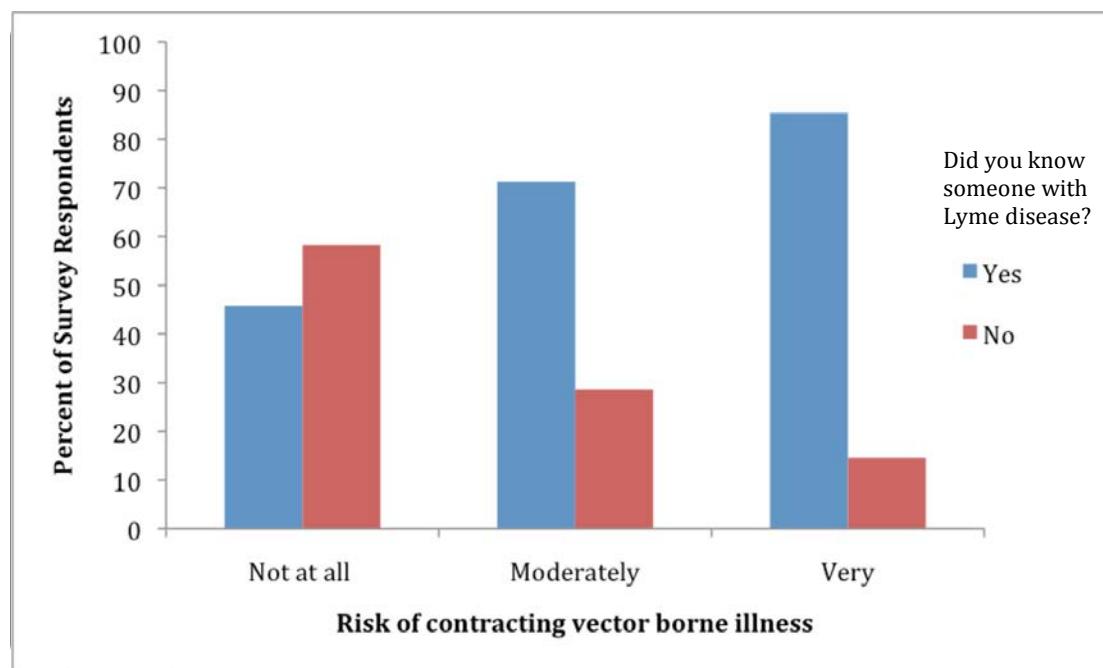


Figure 4: Percent of survey respondents who answered either not at all, moderate, or very likely as the perceived risk of contracting a vector-borne illness and whether the respondent either knew someone with Lyme disease (yes) or did not know someone (no).

Behavior Adaptations

In order to examine how often people are adapting their behaviors, the survey asked respondents to quantify how often they alter activities during the spring and summer to prevent contracting a vector-borne illness. The majority of survey respondents either never altered their activities (35.3%) or altered activities once a week (35.6%). Only one person altered their activities most days. With this data, we can see that “never” and “weekly” are the two peaks among responses. *This shows that the data has a bimodal distribution, where either respondents take adaptive behaviors regularly or they never do.* Many fewer people in the middle are making infrequent changes. We also found that, for the most part, people are not adapting behaviors daily.

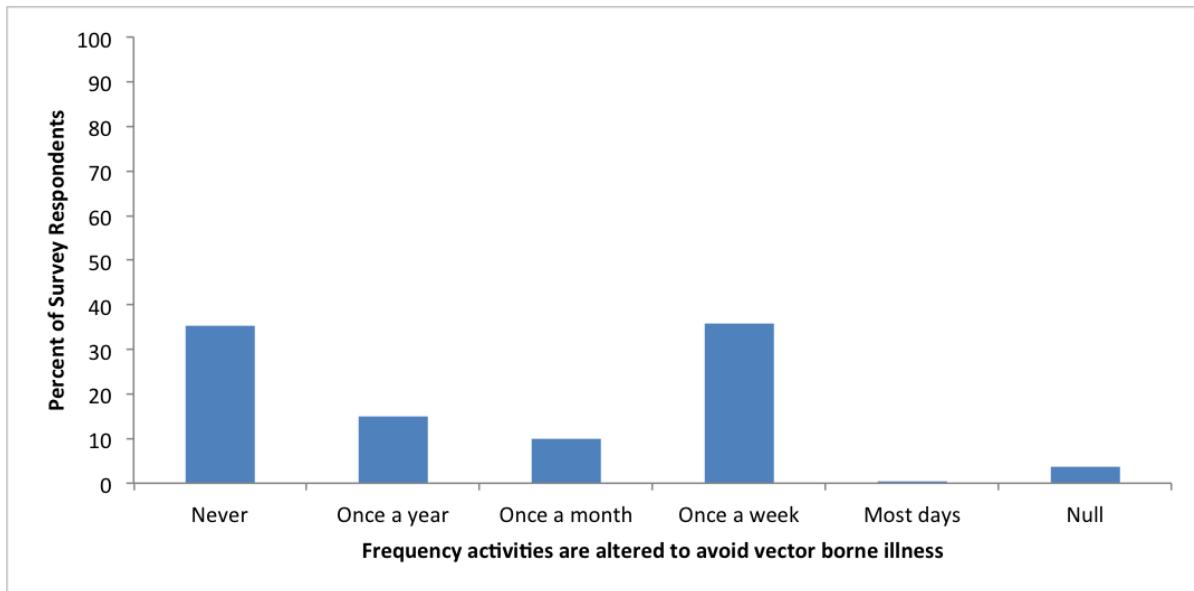


Figure 5: Percent of survey respondents who alter their activity to avoid contracting a vector-borne illness.

Risk perception and behavioral adaptations:

Looking at the relationship between the number of times people alter their activities and how likely they think it is they will contract a disease, respondents who alter their activities once a week thought there was a moderate (57.3%) or very likely (29.1%) chance of contracting a vector-borne illness. Only 1% of respondents who alter their activities once a week thought there was no risk. Of the respondents who never altered their activities, most respondents thought there was moderate (55.7%) to no risk (20%) of contracting the disease. It is probable that respondents with a higher perception of the risk of contracting a vector-borne illness are more likely to alter their activities. *This result indicates that no matter how often people alter activities, there is a general consensus that they are at moderate risk for contracting a vector-borne illness.* This is also informative about people's behavioral adaptations. This graph shows that respondents feel that they are at moderate risk, but are still never changing behaviors. A finding like this highlights one of the problems with adapting to environmental changes: it takes time and effort to adapt your behavior.

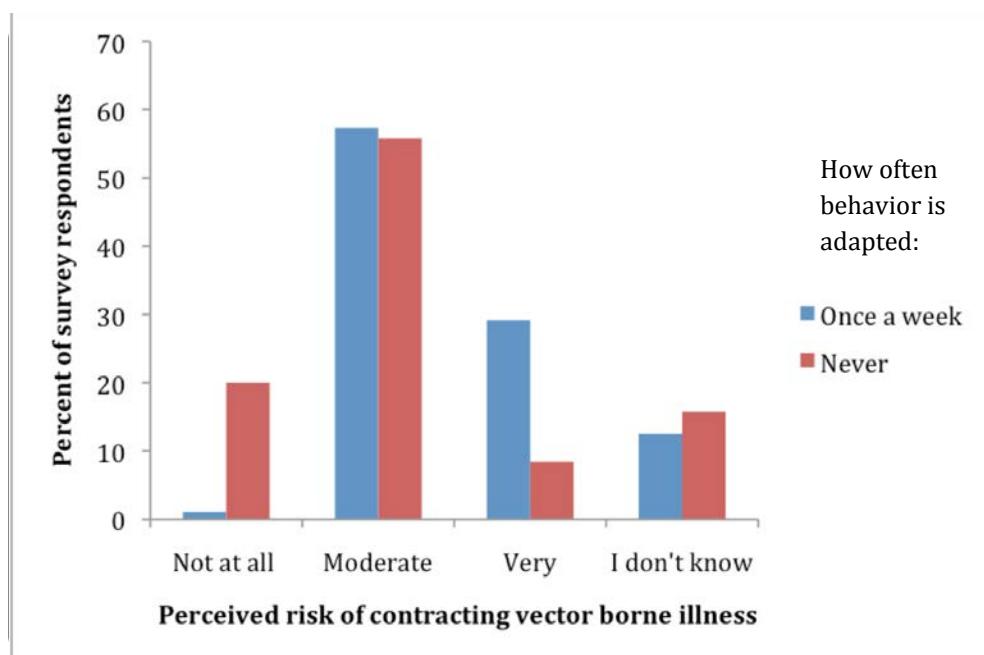


Figure 6: The perceived risk of contracting a vector-borne illness correlated with how often a person adapts their behavior to avoid contracting the illness in the spring or summer.

Types of adaptive measures taken:

Respondents had seven different choices of adaptive measures to prevent tick and mosquito-borne diseases. These measures included applying chemicals, avoiding tick prone areas, adapting clothing, and checking for ticks after outdoor activities. The most common adaptive measure was to check for ticks daily (83.3%). People also were likely to take a shower after being outdoors (63.6%) and avoid high grass and tick habitat (68%). More than half of respondents were likely to adapt by altering their clothing—61.3% were likely to wear long, light-colored clothing, high socks, and boots, and 52.6% indicated that they tuck in shirts and pants. The two most common adaptations were checking for ticks and taking a shower. We were not surprised to find that the most common adaptations were also the easiest to take and did not require substantial behavioral changes. It is important to consider that people may be aware that they need to take adaptive measures, but the actual act of taking some of these measures requires time and effort. *In light of these data, we argue that communication about risk and adaptive measures focus on steps that are easy to take, but have significant value in terms of protection.*

The least common adaptive measures were the use of pesticides and DEET. This could be the result of the perceived negative health effects of pesticides and DEET; in fact, several people made comments about the harms associated with these chemicals on the survey. People must balance the risk of contracting a vector-borne illness and the risk of the chemicals used to prevent that illness. *We would recommend that communication materials about protective measures provide accurate information about the actual risks associated with DEET as well as alternative options for people seeking a different insect spray.*

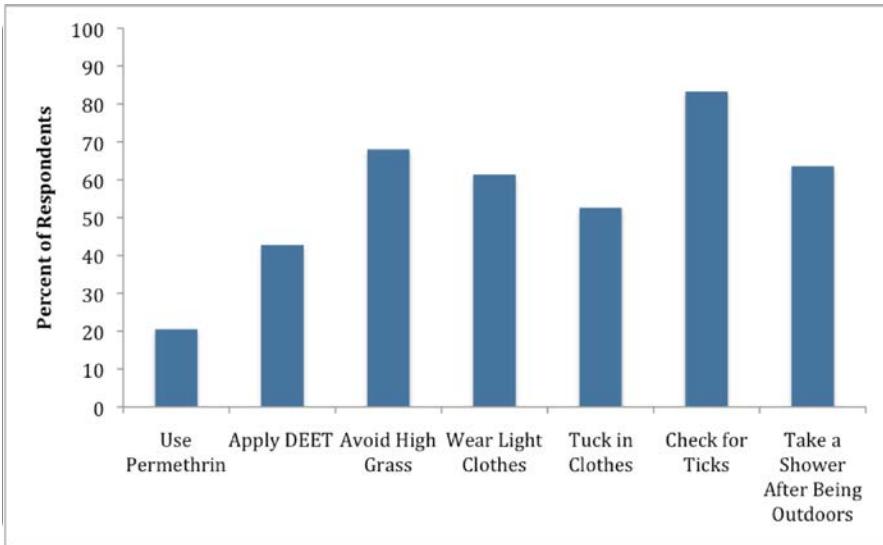


Figure 7: The different types of adaptive measures taken to avoid contracting a vector-borne disease and the respective percentages of each participant who took the adaptive measure.

Number of adaptive measures respondents take:

In addition to examining *which* adaptive measures people were taking to avoid contracting a vector-borne illness, we were also able to quantify *how many* different adaptive measures each respondent was taking. Most respondents were taking at least one action. Only 7% of people were either taking no adaptive measures or did not answer the question. Over 63% of respondents were taking at least four or more different types of adaptive measures. 23.9% of respondents took five adaptive measures; this was the most common result.

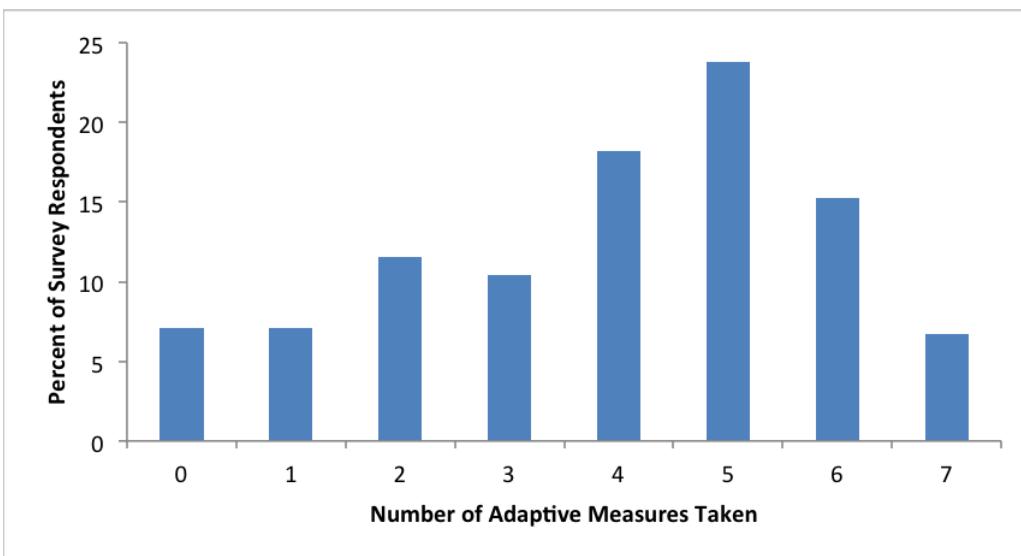


Figure 8: Percent of survey respondents who took the corresponding number of adaptive measures to prevent contracting a vector-borne disease.

Adaptive measures and risk:

We examined how the number of adaptive measures taken corresponded to the perceived risk of getting the disease (question #3 in the survey). This correlation examines the connections between peoples' perceived risk and the actual behavioral adaptations they make. The most prominent result surrounded the group who thought it was not likely that they would get a vector-borne illness. 20% of the people who thought that they were at low risk were taking no adaptive measures (Figure 9). Surprisingly, a similar number of people who thought they were at low risk were also taking four (20%) and five (24%) adaptive measures. Those who thought there was moderate risk were taking between four and five adaptive measures, with the most common number of measures being five (Figure 10). Those who thought it was very likely were taking between three and seven adaptive measures, with the most common number also being five (Figure 11).

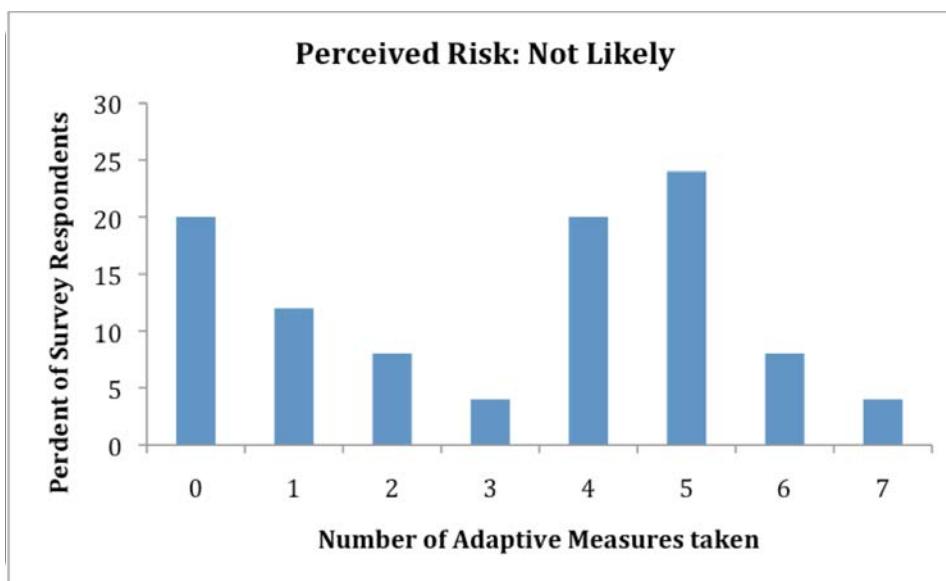


Figure 9: Number of adaptive measures taken by those whose perceived risk of contracting a vector-borne illness was indicated as “Not Likely.”

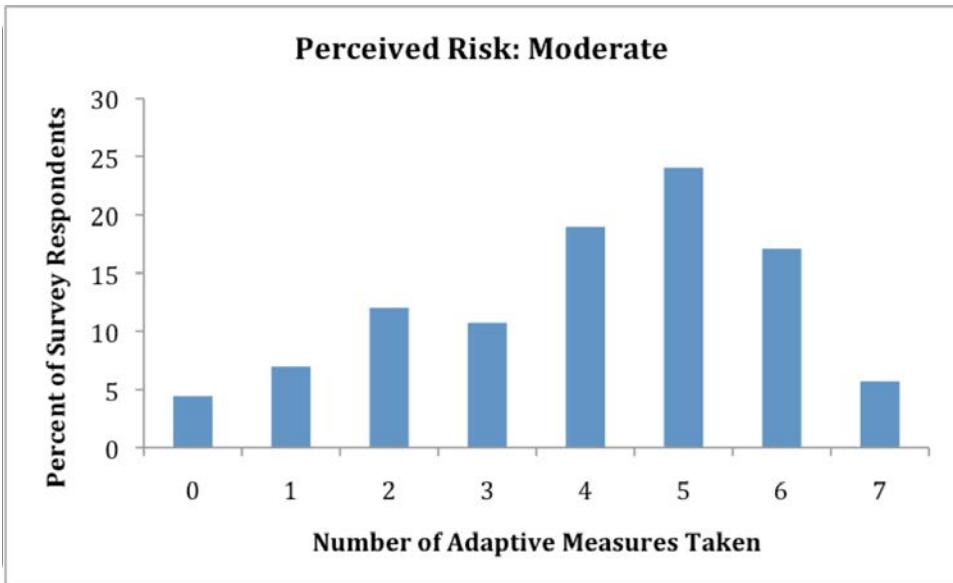


Figure 10: Number of adaptive measures taken by those whose perceived risk of contracting a vector-borne illness was indicated as “Moderate”.

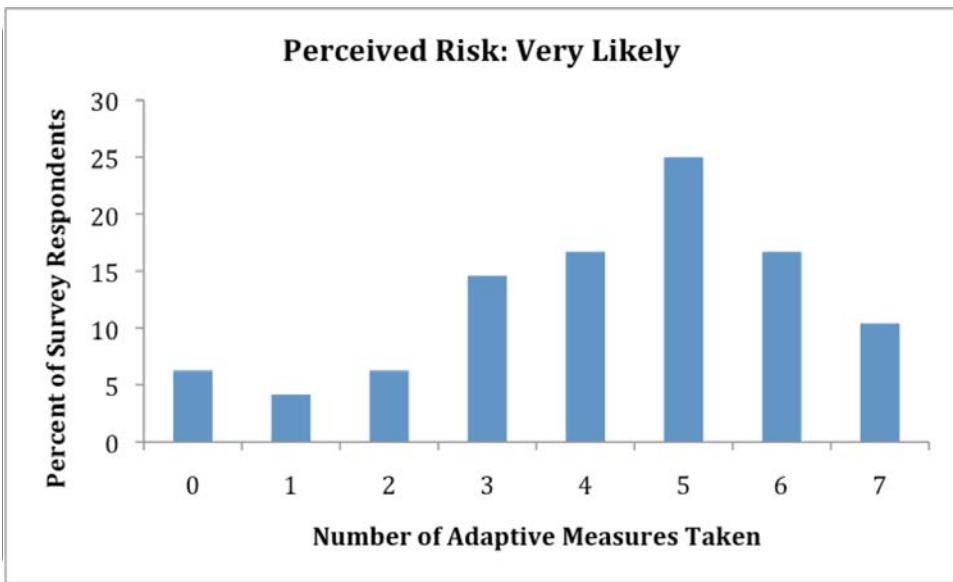


Figure 11: Number of adaptive measures taken by those whose perceived risk of contracting a vector-borne illness was indicated as “Very Likely.”

After examining all three relationships individually and together, an interesting result here is the spread of the number of adaptive measures for people who thought it was very likely. We found no obvious or consistent number of measures that most people took. It is also interesting that the most common number of adaptive measures was five for all three risk categories. Looking at Figure 12, we can see that there are no significant trends in the risk levels

that people perceive and how many behaviors they take. *The result that, for all three risk categories, the most common number of adaptive measures was the same is also interesting because it shows the difficulty in taking adaptive measures, even when you know that you are at risk.* It is hard to change behaviors in order to avoid the future possibility of contracting a vector-borne illness when that adaptation takes time and effort. We suggest that the VDH continue to provide communication materials that provide simple and easy ways to avoid contracting vector-borne illness, like checking for ticks after hiking or avoiding high grass areas. If people see that there are easy and simple solutions, they will be more likely to take adaptive measures and thus reduce their risk of contracting a vector-borne illness.

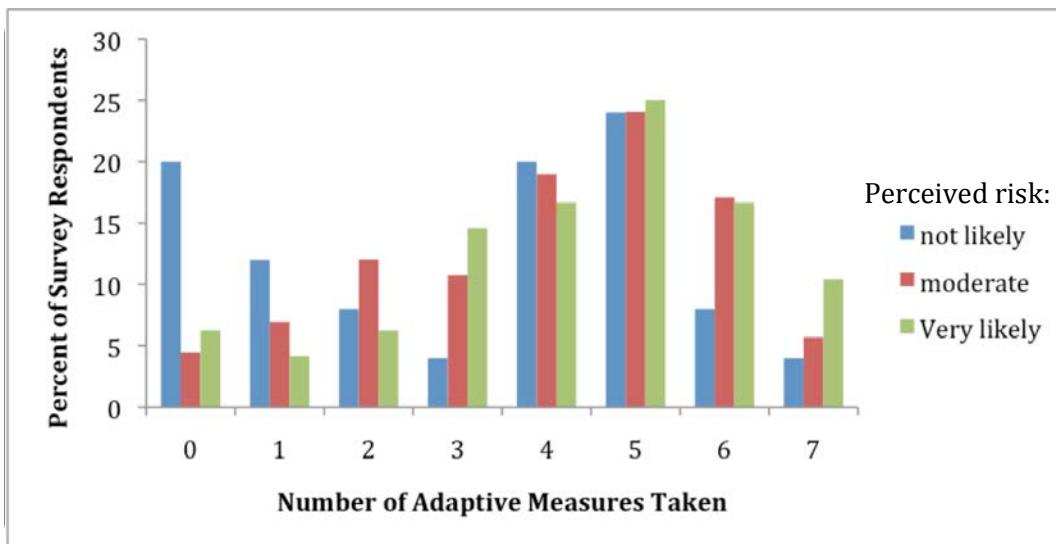


Figure 12: Percent of survey respondents who took each number of adaptive measures based on the perceived risk of contracting a vector-borne disease. This graph is a combination of Figures 8-10 to visually represent the differences.

Outdoor professions and behavioral adaptation:

Many of our survey respondents were not in outdoor oriented professions, but we wanted to look at how many adaptive measures were being taken by those that spend a lot of time outdoors for work and whether we would find an uptick in the number of preventive steps taken by those who spend a significant time outdoors. Of the respondents in outdoor professions, the most frequent number of adaptations was five (22%). Many of these respondents were taking between one and six adaptive measures (Figure 13). *Our data suggest that profession does not necessarily correlate with adaptive behavior, although further studies with larger sub-populations might reveal correlations that our data did not demonstrate.*

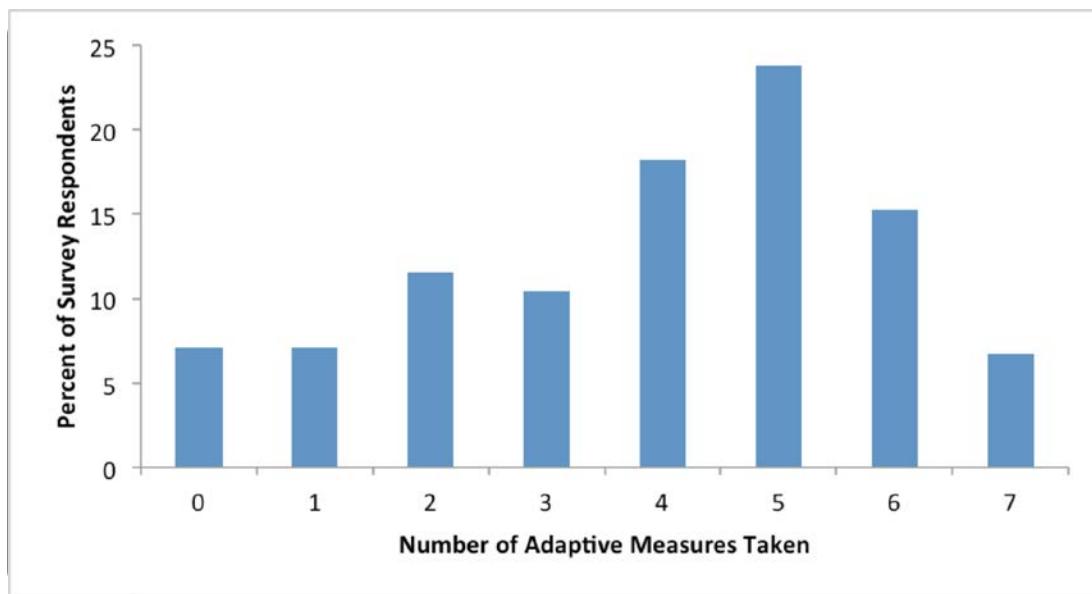


Figure 13: Percent of survey respondents in outdoor-oriented professions and the corresponding number of adaptive measures taken.

Adaptive behaviors and frequency of adaptation:

We examined how the number of adaptive measures taken corresponded to the frequency of altering activities in spring/summer (daily, weekly, monthly or never). For those who never altered their activities, respondents most often took between zero and three adaptive measures, with most people taking two. For respondents who altered their activities once a month or once a week, the highest percentage of people took four adaptive measures. Respondents who alter activities most days took four and five adaptive measures. *Interestingly, of the people who never alter activities, there was a large spread in the number of adaptive measures taken. This means that although these respondents are never altering activities, adaptive measures are taken in an inconsistent fashion.* Of those taking seven adaptive measures, the majority of respondents said they alter activities most days. Another surprising result was that people who alter activities once a month or once a week take a similar number of adaptive measures, despite these very different time frames. These results show that there is not a consistent correlation between the number of adaptive behaviors taken and the frequency of adaptation.

Average number of adaptive measures:

In order to further investigate these trends, we looked at the average number of adaptive measures people were taking, instead of the most frequent. This information paints a slightly different picture: those that indicated that they never alter activities were taking an average of three adaptive measures, those who said once a month were taking an average of four adaptive measures, and those who said once a week and most days were taking an average of 4.5 measures. *This information indicates that most people are taking around four of the adaptive measures indicated in the survey, but those who never alter their behavior are taking fewer precautions to avoid contracting a vector-borne illness.* We recommend that communication materials target people who are taking fewer precautions by emphasizing the importance of protecting oneself against vector-borne illness. Paired with this information could be easy adaptive measures that people can take, in order to encourage adaptation while showing that it doesn't have to be time consuming or difficult.

Adaptive Measures and Demographic Data

The next section examines how the number of adaptive measures corresponds to demographic information asked at the end of the survey. The goal of this analysis is to examine whether different groups of people are acting differently, based on age or income. It could be that some people are not taking certain adaptive measures because of their age. For example, multiple people indicated that they do not spend time outside because they can't walk, so they take none of the adaptive measures.

Tables 1 and 2 examine how the number of adaptive measures taken corresponds to demographic information about age and income for the subset of survey respondents that provided this information. For example, 10% of people in the 18 and below age category use Permethrin to avoid ticks and mosquitoes and 29% of people 19-40 use Permethrin. Across age classes and income categories, the most common adaptive measure was checking for ticks.

Table 1: Percentage of people in each age class taking each adaptive measure.

	Permethrin	DEET	Avoid high grass	Light clothes	Tuck shirts in	Check for ticks	Take showers
18 and below (n=20)	10	20	65	65	50	85	65
19-40 (n=55)	29	40	73	58	49	96	78
41-60 (n=93)	18	48	67	65	55	85	68
61 and above (n=96)	23	45	71	62	56	78	55

Table 1 indicates that the most common adaptive measures across age groups include checking for ticks and taking showers. Every age group also commonly avoided high grass areas and wore light clothes. Tucking in shirts was less common, with around half of participants taking this action. One interesting trend is that respondents 18 and below used DEET a lot less frequently than people in the other age categories. We found that across age groups people were taking similar adaptive measures. Additionally, anti-tick chemicals are the least used adaptive source, indicating that this form of adaption is not appealing to respondents. *We recommend that the VDH not focus on anti-tick chemicals, or, provide alternatives for people to use that they will view as less harmful.*

Table 2: Percent of people in each income class taking each adaptive measure.

	Permethrin	DEET	Avoid high grass	Light clothes	Tuck shirts in	Check for ticks	Take showers
\$10,000 or less (n=30)	13	50	57	70	60	90	60
\$10,001-36,000 (n=69)	17	38	67	64	54	88	65
\$36,001-90,000 (n=93)	24	40	73	59	55	89	65
\$90,001 or more (n=44)	30	52	77	68	50	80	73

Table 2 shows that across income levels, checking for ticks, taking showers, wearing light clothes, and avoiding high grass were the most common adaptations. People making \$10,000 or less avoided high grass less often than those in other income categories. People making \$10,000 or less or \$90,001 or more were more likely to use DEET than people in the middle two categories. *These trends show that there is no obvious differences based on income in the types of adaptive measures people are taking.* This result indicates that targeting specific income groups would not be particularly effective, therefore communication materials should focus on a general audience, instead of targeting income-levels independently.

Awareness of Environmental Changes

Question 7 asked people if they were aware that Lyme disease has increased in the past decade. We found that most people indicated that they were aware of the increase in Lyme disease and have a general understanding of changes in Lyme disease over the past decade (Figure 14). *This result shows that respondents are aware of changes in the frequency of Lyme disease and indicates that this knowledge has penetrated the community.*

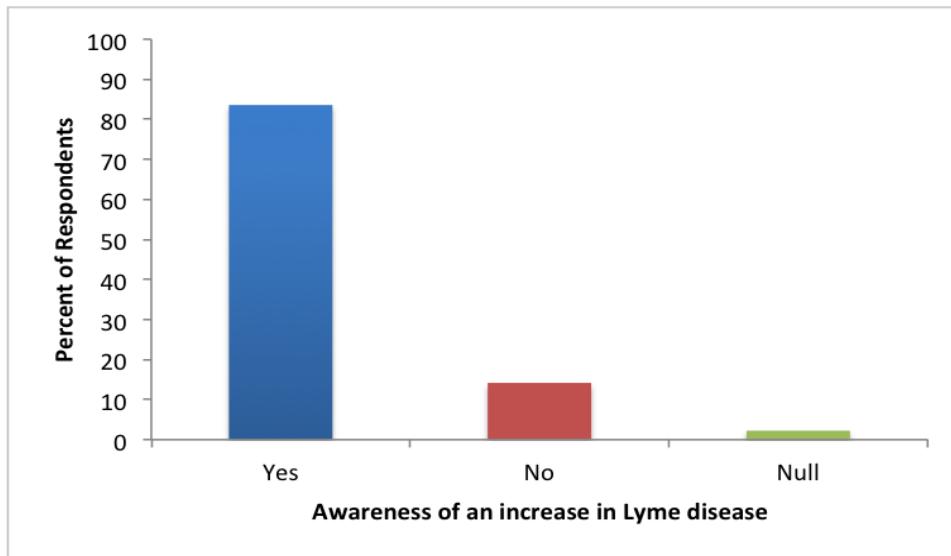


Figure 14: Survey respondent awareness about the increase in Lyme disease.

Awareness and demographics:

In order to examine which people were *unaware* of the increase in Lyme, we correlated demographic data to these respondents. Resulting trends should be helpful in targeting specific populations for awareness campaigns. Most of the people unaware of the increase were in the \$10,000 or less income bracket. There were totals of 15 unaware people in the \$10,000 or less bracket, 4 people in the \$10,001-36,000 bracket, 8 people in the \$36,001-90,000 bracket, and 7 people in the \$90,001 or more bracket. By age, those who were unaware of the increase were mostly in the 18 or less age group. There were 16 unaware people in the 18 or less age group, 10 people in the 18-40 age group, 4 people in the 41-60 age group, and 8 people in the 61 and above age group. The findings do not reveal any important trends associated with a respondent's profession. *This is important because it means that a lack of awareness of Lyme disease can be found across income and age brackets.*

Awareness of increase in Lyme disease and perceived risk:

We further examined those people unaware of the increase in Lyme disease by seeing how they perceived their risk of contracting the disease and how many times they change their behavior (questions #3 and #5). Of the people who were unaware of the increase in Lyme disease, most of them thought there was a moderate risk of contracting the disease or they did not know if there was any risk. No respondent thought there was a very high risk. Most of the respondents never alter their behavior to avoid contracting a vector-borne disease. *These results*

are significant because it means that the people who were unaware of the increase are not adapting behaviors to avoid contracting the disease. For these people, an increase in awareness could lead to an increase in adaptation. *We recommend that the VDH communicate about the rise in Lyme disease as a mechanism to increase adaptive measures.* It is also possible that awareness of the increase of tick-related illness has no bearing on adaptation and that the data we found has more to do with people who—regardless of their awareness of an increase in Lyme disease—might not be willing to make the adaptations. Taking adaptive measures requires effort and time, making them difficult for people to integrate into everyday life.

Perceptions of why Lyme disease is increasing:

We found that 65% of respondents said “climate change” or “warming winter” as a reason for the increase in Lyme disease (Figure 15). However, an answer of climate change does not imply that the respondent believes that climate change is anthropogenic and not naturally occurring. Given this, we can only assume that the respondent meant that changes in weather caused the increase. *If we combine responses of climate change and warming winters, we find that an overwhelming majority of respondents indicate a warming climate as the reason for an increase in ticks* (Figure 16). This is a significant finding because it shows that our respondents are making the connection between warming weather and the spread of ticks.

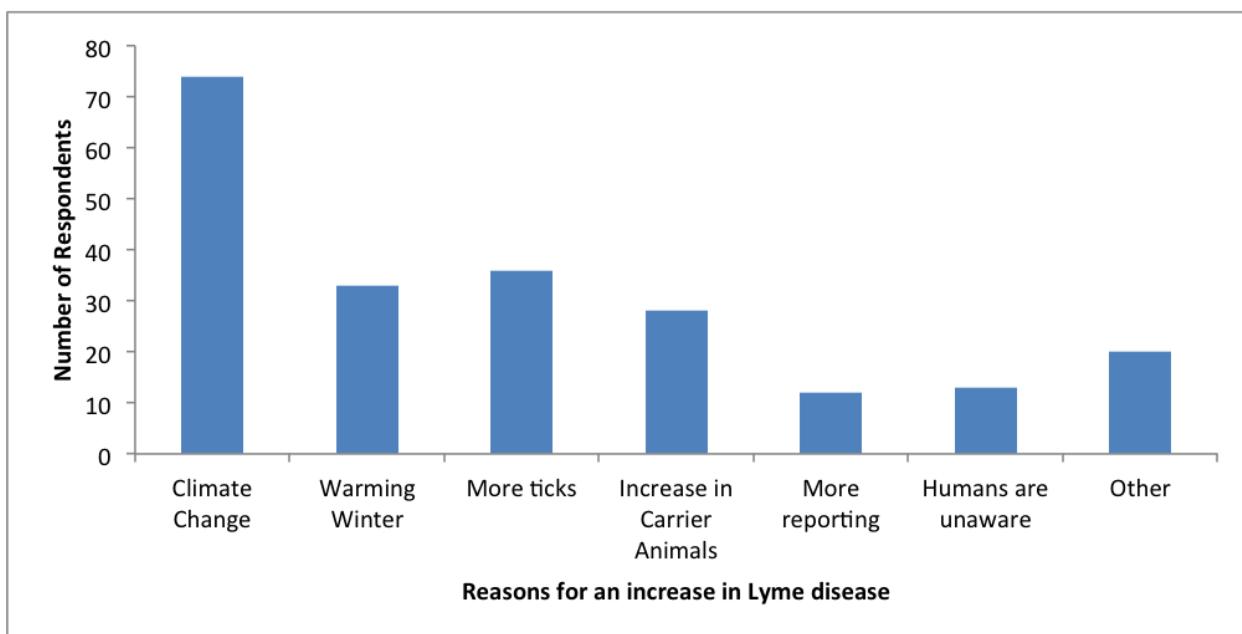


Figure 15: Reasons attributed to an increase in Lyme disease.

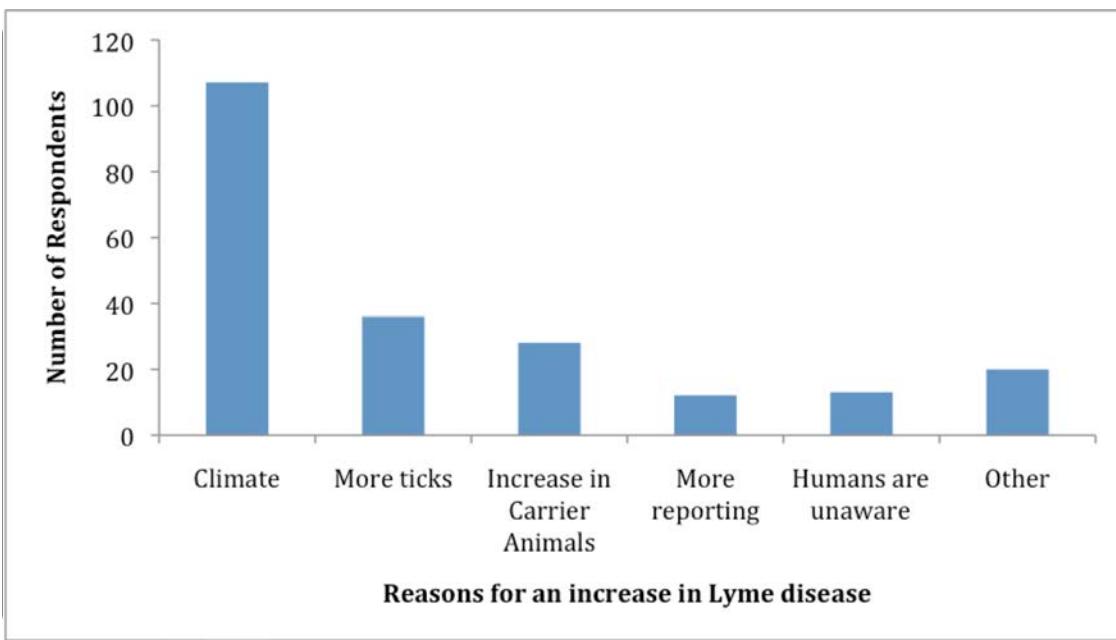


Figure 16: Reasons attributed to an increase in Lyme disease with climate change and warming winters collapsed into one category as “climate”.

Based on Figure 16, we looked at what income, gender, and age demographics were attributing climate change as a cause for the increase in ticks, to see if there are any differences based on demographics. There was no difference across; 66% of males and 63% of females indicated climate change or warming winter. For every income bracket, the most frequent response attributed an increase in the population of ticks to climate change or warming winter. Of the people that made \$10,000 or less, 34% said climate; for people making \$10,001-36,000, 44% said climate; for people making \$36,001-90,000, 40% said climate; and for \$90,001 and above, 48% said climate. We also looked at what each age category attributed as the reason for an increase in Lyme disease. People 18 years old or under did not have a consistent response. For the other three age categories, climate change or warming weather were the most frequently stated reasons for the increase.

The above information looks at all of the survey respondents. We then refined this analysis, looking only at those who indicated climate change or warmer weather as a cause for the increase. Of the people who said climate change was causing an increase in Lyme, 11% made \$10,000 or less, 28 % made \$10,001-36,000, 34% made \$36,001-90,000, and 17% made \$90,001 or more, and 9% of people did not report demographic information. Based on the percentages of people that were aware, this result shows that those most informed about this potential risk are in

the \$10,001-36,000 and \$36,001-90,000 income brackets. For age classes that indicated climate change as a cause of the increase, 4% were 18 or less, 21% were 19-40, 35% were 41-60, and 37% were 61 and above, and 2% did not provide age information.

We examined what the professions of the respondents were who indicated climate change as a reason for an increase in Lyme disease. Teachers (including professors) and business people (accountants, restaurant professionals, retail, consultants) were most likely to say climate change was causing the increase. People in outdoor professions, like gardeners or landscapers, did not have a consistent reason for the cause of the increase. Profession did not have a correlation with a person's reasoning behind the increase.

In looking at the reasons that each person attributed to the increase, there were two other common responses: an increase in animals and an increase in the number of ticks. These two connections are important because they show that even if people are not making the connection directly to climate change, they are aware that change over time is occurring. While an increase in animals is not documented as a cause of an increase in Lyme, this idea is somewhat logical. If there are more animals, and ticks thrive by using these animals as hosts, then there is an increase in suitable habitat for ticks to live and reproduce. Similarly, when people answered that an increase in ticks caused the increase in Lyme disease, this result was logical because if there are more ticks, there would be an increase in Lyme. What this answer doesn't address is *why* there are more ticks, which means that these people were still noticing patterns while not making a direct connection to climate change.

Many people thought an increase in Lyme was caused by an increase in case reporting. The issue of reporting is complicated for several reasons. There has been a change in the case definition of Lyme disease over time, resulting in minor changes in how Lyme is diagnosed. In addition, it can be difficult to diagnose Lyme disease and tests can report false negatives. Further complicating the reporting process, there is also controversy about chronic Lyme disease. It is important to note that the people who indicated changes in reporting were highlighting an issue that has become more pressing with the increase in Lyme disease.

Communication Methods

The survey presented a number of communication sources and asked respondents to indicate the frequency at which they were using different sources (Table 3). Sources used on a

daily basis included the internet, word of mouth, and television/radio. The internet was indicated as the most frequently used source for daily information, suggesting that this is a form of communication that should be targeted. Many people indicated that they get information through word of mouth, as 38% of respondents use this source monthly. Television and radio were reported as sources of information used daily and weekly. Of the survey respondents, 48% never get information from school and work, suggesting that these are not reliable means of communication about vector-borne diseases. Doctors' offices were not regularly used sources of information on vector-borne disease; however, many people (47%) got information once a year from their doctor's office. This suggests that although doctors are not a regular source of information, it is beneficial to have information at the office for yearly visits.

Our survey found that only 3% of people use the Vermont Department of Health website on a daily basis and 4% do so weekly. 41% of respondents have never used the VDH website and 28% use the website once a year. Our survey also found that most people never get information from community groups (51%) or only do on a yearly basis (16%). Based on these estimations, *we recommend that the VDH capitalize on the sources people are already using the most in order to disseminate information quickly. Additionally, we recommend that the VDH target the underutilized communication sources in order to reach an even broader public.* Increasing peoples' awareness of new sources of information such as school/work and community groups could be done using the sources people are using daily and weekly such as the newspaper and radio.

Table 3: Number of respondents who use each form of communication

	Newspaper	TV/Radio	Doctor	School/Work	VDH	Internet	Word of Mouth	Community
Never	44	38	72	129	110	51	17	136
Yearly	85	78	126	53	75	48	50	43
Monthly	68	71	28	29	27	73	103	28
Weekly	34	34	11	11	9	32	43	14
Daily	20	31	8	8	11	43	36	15
Null	18	17	24	38	36	20	19	31

To further evaluate the sources of communication, we broke down the numbers of respondents for each category by demographic data. First, we looked at what sources of communication people were using either weekly or daily by age group. For all four age groups, the internet and word of mouth were used most frequently. For people 18 and under, the internet and word of mouth were the only two categories used weekly or daily. Community groups and the VDH website were used the least often, with 50% and 45% of respondents 18 and under saying they never use these sources. For people 19-40 and 41-60, TV/radio, internet, and word of mouth, were the most frequently used sources. Community groups were the least used, with 60% of respondents aged 19-40 and 57% of respondents aged 41-60 indicating that they never use community groups for information. For people 61 and above, newspaper, TV/radio, and internet were the most popular sources. It is important to note that for this age group, many participants did not answer the questions for both school/work, VDH website, community groups, word of mouth, and internet. A high percentage didn't answer the questions because they do not use these sources. Instead of putting never, many people wrote at the top of the survey that they did not use these sources. For example, if someone is retired, they did not circle anything for school/work instead of writing never. This is important to keep in mind when looking at these results. For older populations, school/work was indicated as the least frequently used (62%). Based on these results, some sources are better than others depending on what age group you are targeting. If the

goal is to reach more young people, the internet is a good communication source. Print media in the newspaper and TV/radio broadcasting are the best methods to target older populations. In summary, our findings are that most people are using the internet and word of mouth; if the goal is to target the largest audience, those sources will be the best to use.

When examining communication use across income levels, we found that those earning \$10,000 or less use word of mouth, the doctor's office, and the internet most frequently. People earning \$10,001- 36,000 used TV/radio, word of mouth and the internet most frequently. Those earning \$36,001-90,000 used TV/radio, newspaper, and word of mouth most frequently. Finally, people earning above \$90,001 used the internet, word of mouth, and TV/radio most frequently. There are some interesting trends to be picked out of the most frequent source of communication; the lowest income bracket was the only one that used the doctor's office as a source of information as regularly as other sources. Those in the \$36,001-90,000 were the only ones to use the newspaper as regularly as other sources. All groups except those earning \$36,001-90,000 used the internet regularly, and every group frequently used word of mouth. *The least used sources were consistent across all income brackets; these included community groups, the VDH website, and school/work.*

Another demographic question we asked was about the gender of our respondents. In looking at how males and females responded differently, the first observation is that the genders were disproportionately represented with 175 female and 86 male respondents. *We found that the most and least frequently used sources did not differ based on gender.*

In addition to looking at demographic information, we looked at how sources of communication correlate to risk perception and adaptive behaviors, as indicated by question #3 and #5. For question #3, people either indicated that they had no risk, moderate risk, or a very high risk of contracting a vector-borne disease. For those who thought they had no risk of contracting a vector-borne disease, the most frequently used sources of communication were newspaper, TV/radio and internet. The least used sources of this “no-risk” group were community groups, school/work, and doctors’ offices. For those who indicated a perceived moderate or very high risk, their most used sources were word of mouth, internet, newspaper, and TV/radio. The only difference between these perceived risk groups was that *those who perceived no risk did not use word of mouth as a communication source. Respondents that*

indicated no risk were also more likely to never use the doctor's office as a source of communication, while the other risk levels both used doctors' offices yearly.

We also looked at how altering behavior to avoid contracting a vector-borne illness correlates to communication sources. Those that altered their behavior weekly used word of mouth and TV/ radio most frequently, while those who altered behavior most days used internet, TV/radio, and word of mouth. Those that use the internet to get information about vector-borne illness weekly or daily more frequently adapt their behaviors.

Verbal Survey

Using brief verbal surveys and a suite of five maps (Appendix B), we collected information on the relative impacts of various methods of visual data representation. Specifically, our goal was to assess the potential that particular graphical features, scales of geographical representation, and frames of risk portrayal held to engage viewers in understanding their risk for Lyme disease.

Use of Color

Of the 42 people surveyed, 62% percent identified the red-yellow-green color spectrum to be a clear and effective feature in communicating risk. This color scheme—found in maps 3 and 4—was identified to effectively make people feel at risk and also as a clear way to communicate the risk data. Specifically, the color spectrum was identified as “intuitive”, “clear”, and made the message of the map “easy to grasp quickly.” There was also criticism of other color schemes in other maps (1, 2, 5). The blue gradient—found in maps 1 and 5—was criticized as not clearly communicating risk. Blue was identified as being “too calming” of a color for the level of risk being communicated. Seven individuals also commented that the same maps (1, 5) would be more effective if they used red, rather than blue.

There were mixed reviews on the use of color in the Tick Tracker (map 2). While the red coloration was understood as communicating risk in deer ticks, participants were confused if other ticks—represented by other colors—also presented a risk, and to what degree. The map was also identified as “too busy” and “distracting” because of the number of other data points in differing colors. If this map were to be used for communicating about Lyme specifically, excluding data points about other tick species might help its clarity. The map would also benefit from using a color gradient to communicate the relative risk of each type of tick to humans.

Individual Data Points

The Tick Tracker map (2) was the only map we presented that showed individual data points for evaluating risk. Participants identified the use of these individual data points as a clear method for communicating risk. Individual data points helped individuals see how risk was distributed throughout Vermont counties and they were helpful in assessing personal risk. The Tick Tracker map was identified as the most helpful for assessing personal risk in 18 of 42 participants. Five individuals identified that the density of the dots in an area increased their perception of risk; they felt more at risk if their home was in an area with high dot density.

Several individuals, however, also indicated a mistrust of the Tick Tracker map. One individual said, “I don’t believe this one, it’s just where people are,” indicating mistrust in self-reporting for personal risk analysis. Another respondent echoed this concern, identifying an area with few dots as mountainous, and speculating that not as many people would be in this area to report ticks. A third respondent did not like the map because it created “false safe zones.” Their fear was that people might believe themselves to be safe in areas where few ticks had been reported, but this reporting might not reflect the actual risk or distribution. This map was the only map where participants indicated mistrust for the data represented.

Geographic Specificity

Three of the maps (1, 2, 5) only showed the state of Vermont. These maps also showed county boundaries, and map 2 was even broken down to show the town limits within counties. Half of the respondents (21) identified the geographic specificity of the state and county lines to be helpful in assessing risk. The breakdown by county was identified as “useful”, especially in assessing personal risk based on the county they lived in. No positive comments were made on the inclusion of town lines, in the Tick Tracker maps and two individuals actually felt that they were “unnecessary” relative to the other information that was conveyed.

Geographic Context

Geographic context was also identified as important to understand and interpret Lyme disease risk. Of the 42 people surveyed, 19 identified that map 4 made them feel most at risk. One of the features identified in helping communicate this risk was being able to see the risk in Vermont and New England with the context of rest of the country. Geographic context was also

identified as an important element for clear communication of risk and in assessing personal risk. This element seemed to be especially important to people who had lived in other areas of the country or regularly visited other states. We observed several individuals checking the risk in the other regions of the country that they commonly visited or where they had previously lived.

The Importance of Relative Risk

One trend that emerged from our observations was the importance of relative risk in risk assessment. Both on a spatial and temporal scale, people seemed to be more alarmed and feel more at risk when the maps showed that they were at higher risk relative to other areas or periods of time. Looking at map 1, one participant said, “I really wouldn’t want to live in Rutland.” When prompted, they explained that they would be more at risk to get Lyme because Rutland was dark blue, when Addison County was a lighter shade, so they felt less threatened. In this case because the relative risk was presented to be higher in a different area, they discounted their own risk. Map 4 seemed to increase participants’ perception of risk. One participant stated that map 4 was “scary” because the risk was concentrated in New England, while the rest of the country was “safe”. Map 3, which used the same data but only showed New England, did not communicate the same level of risk. Most of the map was red, but Vermont “had less red” than the rest of the states shown, so “Vermont [was] not as bad”. The same was true for the trend over time. People identified higher perceptions of personal risk when they could see that risk had increased over time (5) than when they were presented with just the 2013 map (1). Several individuals reacted with surprise when presented with the change over time map (5). One individual reported, “Its scary, because the problem is getting worse”. Respondents’ perception of risk was elevated when they were made aware that the level of the risk was not constant, but had increased and that this increase is predicted to continue. Because the present and future risk is higher relative to past levels of risk, the potency of perceived risk increased.

Focus Groups

The focus groups we organized proved to be one of the most important sources of our recommendations and our primary avenue for connecting with the very community from which we strove to learn. The atmosphere of these gatherings was always pleasant and welcoming, with an air of calm energy, which was probably also attributable to the quiet settings and the early

morning hour of our meetings at Carol's Hungry Mind Cafe in downtown Middlebury. The further we got into the discussions, the more passionate voices we heard from our participants as they started to express their frustrations about the inaccuracy or inefficiency of certain communication techniques. The small size of the groups helped to quickly cultivate a sense of trust among participants. We often did not expect the level of personal detail participants ended up sharing with us, and we were truly grateful for their trust and honesty.

As part of our focus group discussions, we asked our participants to fill out a survey consisting of seven short questions. We first asked about our participants' initial perception of personal risk uninfluenced by our dialogue, next we posed questions about their immediate reactions to the three videos presented, and finally we prompted them to re-assess their personal risk and likelihood to adapt their behaviors after our discussion.

The results of the questionnaire showed first, that the large majority of our participants had been personally affected by Lyme disease either as patients or via a close relative or friend. This means that we cannot claim that our group was a representative sample of the larger Vermont population. When evaluating effective communication techniques, we have to consider both those already affected by Lyme, and thus more informed about the disease, and those who have not yet heard about it or have only a superficial understanding. Had we gathered a group of less informed individuals, we might have been able to steer away from the controversies and focus more on the communication strategies we presented during our discussions. Such a group might have also been more open to discussions about the connection between the increased spread of Lyme and the threats of climate change. We found that personal experiences with the disease made most people rather sensitive during this part of the conversation. However, this does not mean that the general public would react in the same way when presented with the link between the two issues.

On the other hand, a less informed group would have probably required us to spend more time explaining more background knowledge about the disease. While this would have constituted a useful public service on our part, it would have also taken away from the time we could spend really delving into the matter, and looking into very specific elements of communication strategies. However, despite the fact that our groups were not representative of the general public in Vermont, the insights we got from our discussions gave us valuable guidance in writing up our recommendations, as our participants have shed light on many aspects

of communication strategies that we had not considered prior to our focus groups.

We posed two separate questions about the *persuasiveness* and *trustworthiness* of messages presented in the videos. Most people indicated that the personal narratives were the most persuasive and compelling and the doctor's narrative was the most trustworthy one. The reasons for their choices were varied, and participants discerned a great number of crucial communication elements in their analyses of these media. These included perceptions of objectivity and accuracy of the information presented, the emotional appeal of the narrators, and an appropriate portrayal of risk assessment. These points will be addressed in greater depth in our "Recommendations" section.

Another important finding that the discussions provided was that all participants were already taking several preventive measures against contracting another case of Lyme. This finding is consistent with those of our initial surveys that stated that most people with a personal connection to Lyme take at least four preventive measures, with regular body checks being the most common measure. Unlike in our initial surveys, we phrased this question open-endedly and as a result got a list of new strategies. These included steps such as putting clothes in a dryer for 20 minutes on high temperature after time spent outdoors, spraying one's yard with pesticides, and checking pets for ticks regularly. Some responses suggested that several participants have not only thought of avoiding high grass or wooded areas, but also considered limiting overall time spent outdoors. This is of concern, since access to one's natural surroundings has been proven to have a range of beneficial psychological effects. A study published in the journal *Health Promotion International* states that "contact with nature plays a vital role in human health and well-being" and that "public health strategies are yet to maximize the untapped resource nature provides [...] especially in the prevention of mental ill-health" (Maller et al. 2005). This means that simply limiting time spent outdoors, while limiting one's exposure to Lyme, could also have a net negative impact on a person's well being. The potential cost to well-being of limiting one's time spent outdoors lends further validity to our research question, as we aim to help improve communication methods around preventive measures that are effective and holistically beneficial. Finally, two participants mentioned the option of moving to a less risky area. Of course, exercising such an option is only available to those who have the means to move elsewhere which will always be a select few. For this reason, we do not consider such an option as a viable preventative measure. The fact that two participants mentioned this option, however,

shows the severity of the issue here in Vermont and the importance of appropriate communication about not only the risk posed by Lyme, but also about accessible and viable preventive measures.

VII. Recommendations

Recommendations from Initial Surveys

The results of our initial electronic surveys can serve as the basis of several important recommendations for the Vermont Department of Health. Three among these stand out as particularly important findings. First, we found that the most frequently used sources for information about Lyme disease were the internet, word of mouth, and TV/radio. The underutilized sources include the VDH website, school or work and community groups. *We therefore recommend that the VDH capitalize on the sources people are already using the most in order to disseminate information quickly. Additionally, we recommend that the VDH target the underutilized communication sources in order to reach an even broader public.* The VDH's website already offers a substantial amount of useful information on the topic; however, respondents still rated it as an infrequently used source. This means that for those with access to the internet, the content of the site is either not accessible enough in its visual and logical structure or technical language, or that the public is simply not aware of its existence. Therefore, we strongly suggest that the VDH spread knowledge of the website itself, and make any necessary adjustments to the information presented.

A second important finding was that most people either never or weekly alter their activities to avoid vector-borne diseases. Our results showed that more than half of the respondents change their behavior less than once a week. *Given this finding, we recommend targeting the subpopulations that are not currently altering activities by increasing communication to those populations about preventative measures that they can take.*

Our third most remarkable result showed that most people are aware that Lyme disease has increased over the past decade. We then posed the question of why people thought this increase was happening and got a range of responses, out of which the most common was

climate change. A number of people also attributed the increase to warming winters, which shows that people have a baseline understanding of what is causing the increase while not specifically citing climate change as the cause. *Since people are making the connection between the increase in Lyme disease and warmer weather, we recommend that Lyme disease be used as a tangible example to show the negative effects of climate change to communities in Vermont.*

Recommendations from Verbal Surveys

The final recommendations that we can draw from our verbal surveys and observations may be helpful in the creation or selection of maps for future communication about Lyme disease or other environmental health risks:

- Use colors that are intuitive and appropriately communicate the urgency of the risk being communicated. Red was generally understood to communicate risk or mean “bad”, and the green to red color spectrum was easily understood.
- Data points were effective in communicating personal risk, and risk perception was increased when risk points were close to or densely aggregated around the home range of the viewer.
- Geographic specificity is useful to communicate data clearly, but too much specificity was distracting. Showing borders down to the level of town boundaries may be unnecessary.
- Providing larger geographic context was helpful in interpreting risk and added clarity because it showed the scale of the risk across the nation.
- In order to facilitate risk evaluation, use maps that present the data in a way that presents viewers’ risk as high relative to other times or areas.
- Include a combination of maps to show both the larger context and geographic specificity of the target area. Several participants suggested this, and we echo this suggestion. The different scales can present very different information, and the combination of contextual risk with geographically specific risk can increase understanding and perception of personal risk.

Recommendations from Focus Groups

The participants of our four focus groups provided us with many valuable insights about the effectiveness of different narratives in conveying the risks of Lyme disease and the range of communication elements that are needed to reach the greatest possible audience. Some of these confirmed our previously held assumptions, such as the need for pluralistic advocacy, i.e. messages coming from a diverse group of people, representing different perspectives, such as the medical, the scientific, and the personal. Others we did not necessarily foresee, such as the importance participants attributed to the tone of the narratives (i.e. the level of urgency the messages communicated).

Most participants were in consensus that doctors are generally regarded as figures of authority in most communities, meaning that they are perceived to be trustworthy in their accounts. The statistics and other factual information the doctor provided in our video clip convinced most participants of the narrator's objective standpoint. Given the controversies around Lyme, a need for a lack of personal bias on the part of medical professionals was highly emphasized by most participants. Several participants shared recollections of times when doctors presented them with conflicting information that often undermined the credibility of the doctor. These accounts usually referred to the case definitions and treatment options. The repeated use of the words "accuracy" and "clarity" when referring to the doctor's narrative frame further supported this crucial requirement for any communication strategy around Lyme disease.

According to our participants, a higher awareness about the risks of the disease, in itself, would not be sufficient to compel substantive behavior change. Several people pointed out that the messages need to incorporate elements of personal narrative, show a diverse group of patients, and a range of symptoms in more descriptive contexts. They believed that these accounts trigger a sense of empathy and help people understand the real life impacts of the disease more profoundly and in a way that "stand alone" dry, numerical data about cases could never do. Our respondents highlighted a need for diversity of gender, age, ethnicity and professions among those who are conveying information about Lyme. This was supported by the fact that the choice of the most trustworthy character varied for participants, which was most likely attributable to personal preferences. This lack of consensus is therefore a valuable finding, since it highlights the need for a spectrum of characters to be presented for a broad appeal and thus effective messaging. Additionally, several participants agreed that they would especially

welcome these stories from a group of people from Vermont, because they could more easily relate to them. In general, they agreed that more local the references, demographic data and statistics presented are, the greater their sense of personal connection to the issue would be.

The question about the right tone of the messages seemed to be a crucial one as well. Most participants agreed that if our aim is to both raise awareness and facilitate adaptive behaviors to reduce the incidence of Lyme, communication efforts need to strike an appropriate balance between communicating a sense of urgency and personal empowerment. At one extreme, people disliked the seemingly casual, almost nonchalant attitude of the scientist presented in our video, while they also mentioned that the opposite, a highly alarming tone, associated with the doctor's words by some, would not prove effective either. The former would not motivate people enough to take this issue seriously, while the latter could paralyze people into inaction. The melancholic piano music accompanying the personal narratives was also perceived to be too distracting. In other words, the right tone would convey the severity of the issue, but with enough positivity about the potential for preventive behavior adaptation.

One of the participants shared some insights in a follow-up email that added many subtle layers to our analysis of effective presentation styles. She said that one of the main challenges of motivating people to take precautions against Lyme disease comes from the public's distrust of much of the media. In her words:

People in our culture are so bombarded with advertisements (including political messages crafted cunningly as advertisements) which use fear to manipulate them, that they must maintain vigilant filters. One could be easily overwhelmed and paralyzed by fear if one accepted every authority and message on everything from voting to toothpaste. So the challenge in educating the public about Lyme disease is how to package information so that people take it seriously, in a way that doesn't too closely resemble an advertisement bullying them into buying something.

She added that some of the negative reactions our focus group participants had towards the doctor and the scientist might have been related to the number of “white-coated advertising experts out there.” Therefore, we need to account for these personal filters when designing communication materials and ensure that messages come across as authentic and trustworthy.

When asked about visual and auditory aspects of the videos presented, focus group members agreed that creative, well-designed videos with interesting cinematographic effects are more attention grabbing than simple videos, especially when compared to settings such as the sterile environment of the doctor's video. Using short, to-the-point messaging and sound bites

instead of lengthy messages was also recommended. This feedback supports the theory that more information does not necessarily translate into more awareness of an issue; among other considerations, presentation style can distract the audience or the trustworthiness of the narrators can discredit the information presented.

After a focus group, one of the participants shared with us a letter she previously sent to the VDH in which she listed a set of recommendations for their website. Many of her requests came up previously during the discussion and had the support of several participants. These included a need to reorganize sections of the site dealing with Lyme disease information with clearer subsections for easier accessibility and posting additional information about treatment. Participants also agreed the uncertainty surrounding Lyme and chronic Lyme disease needs to be addressed by authorities like the VDH in order to increase the credibility of such organizations.

Overall, participants all agreed that a pluralistic approach is essential for effective communication. They advocated for an integration of the medical, scientific and personal framings into one, more holistic frame. This way the authority of a medical professional would be coupled with the objective findings of a scientist, both triggering a rational response and a higher perception of risks, while the recounting of the personal struggles of Lyme patients could elicit emotional responses that would be needed to compel preventive action from the public beyond simply raising awareness.

Summary Recommendations from Focus Groups

Narrative frame

We found that in order to effectively communicate the risk of Lyme disease to the general public, communication materials need to present a range of perspectives, such as the medical, the scientific and the personal. Each frame has its own benefits. A medical professional can provide objective and accurate data on Lyme disease, prevention techniques and treatment options. A scientific expert can explain the natural context of the Lyme-bearing ticks and the reasons behind the increased spread of these vectors. Personal accounts can show a range of symptoms and the impact the disease can have on one's everyday life. We found that all three perspectives are needed if we aim to raise awareness of the risk of Lyme disease, motivate people to take preventive action, and regard this danger in the larger context of climate change-related public health threats.

Narrative voice

We recommend that messages strike an appropriate balance between communicating a sense of urgency and personal empowerment. This highlights both the seriousness of the issue and the potential for preventive behavior adaptations.

Other Recommendations

Presentation of Information

We recommend that a variety of visual and auditory techniques be used to present information about environmental health risks in order to cater for the needs of different learners, age groups, literacy levels, and language competencies.

Climate Change Communication

We recommend that the VDH communicate the heightened risk of environmental health threats and use this local and increasingly serious public health issue in order to initiate a dialogue in Vermont about climate change mitigation in a broader context.

VIII. Conclusion

What are the implications of our work? As the number of Lyme-carrying ticks in Vermont continues to increase, more effective communication about risk and preventive behaviors will slow, stop, or reverse a correlational increase of Lyme disease in the state. More broadly, the foundation of the VDH's efforts and the impetus for our partnership lies in climate change preparedness and public health adaptation. As the public becomes more aware of environmental health risks and takes preventive behaviors, there exists the potential to create a more personal context for climate change dialogue with formerly environmentally disengaged individuals.

Beyond this project and the scope of our data collection but within the scope of our classwork, we believe that the frame of environmental health risk presents a unique opportunity within climate change communication. Public health issues, a deeply personal implication of climate change, will be shifting alongside temperatures and precipitation patterns. As people are able to more clearly perceive climate-linked health threats to themselves and their immediate communities, they will be increasingly motivated to take climate change action.

Appendices

A. Survey

Middlebury College
Environmental Studies Senior Seminar
Professor Rebecca Gould and Diane Munroe

Survey on Vector-borne Diseases in Vermont

1. Have you heard of (please circle):
 - Lyme Disease? Y / N
 - Eastern Equine Encephalitis (EEE)? Y / N
 - West Nile Virus? Y / N
2. Have you, or a close friend or family member, been infected with Lyme Disease, EEE, or West Nile Virus? If yes, please circle the one(s) that apply.
3. How likely do you think it is that you will get one of these diseases?
Not at all Moderately Very I don't know
4. How often do you get information about environmental health risks such as Lyme Disease, EEE, or West Nile Virus from the following sources?

Newspaper

Never Once a Year Once a month Once a week Most days

TV/radio

Never Once a Year Once a month Once a week Most days

Doctor's office

Never Once a Year Once a month Once a week Most days

School/Work

Never Once a Year Once a month Once a week Most days

Vermont Department of Health Materials or Website

Never Once a Year Once a month Once a week Most days

Internet

Never Once a Year Once a month Once a week Most days

Word of Mouth

Never Once a Year Once a month Once a week Most days

Community Groups

Never Once a Year Once a month Once a week Most days

Other _____

Continued on second page

5. During the spring and summer, how often do you alter your activities or your family's to prevent contracting Lyme Disease, EEE, or West Nile Virus?
- Never Once a month Once a week Most days
6. Have you taken any of the following adaptive measures to prevent tick and mosquito related diseases (circle all that apply):
- Use Permethrin (an insecticide) on outdoor gear
 - Apply DEET to clothing and skin
 - Avoid high grass, wooded or bushy areas, stay on trail
 - Wear long, light-colored clothing, high socks, boots
 - Tuck in shirts and pants
 - Regularly check for ticks
 - Take showers after long periods of time spent outside
7. In Vermont, there has been a drastic increase in Lyme disease over the past 10 years.
- Were you aware of this increase? Y/ N
 - Why do you think this is?

-
8. Is there anything else you'd like to share about your experience or concerns about these diseases?
-
-
-

General Demographic Information

What is your age group?

18 and below 19-40 41-60 61 and above

What is your gender? M F Other

What is your individual income level (choose from tax brackets below)?

\$10,000 or less \$10,001 - \$36,000 \$36,001 - \$90,000 \$90,001 or more

What is your profession (eg. carpenter, teacher, homemaker) _____

Thank you for participating in our survey! Please leave your contact information on the form below if you would be willing to participate in a further interview or discussion group.

Appendix A.1: Specific Limitations of Survey

The following illustrates problems we encountered that were specific to certain questions. Question 1 asks:

1. Have you heard of (please circle):

- Lyme disease? Y / N
- Eastern Equine Encephalitis (EEE)? Y / N
- West Nile Virus? Y / N

After this question, there is no disclaimer stating that if you answered no to all three choices, you should skip ahead to the demographic information or hand in the survey. It is structurally contradictory for respondents to continue filling out the survey when all of the following questions assume awareness at least one of these diseases.

Precision of language was a recurring issue throughout the survey. Question 2 on the paper version asks:

2. Have you, or a close friend or family member, been infected with Lyme disease, EEE, or West Nile Virus? If yes, please circle the one(s) that apply.

Respondents answered this question in a number of ways: they left it blank, circled both the “relationship” (you, close friend, family member) and the disease, just circled the “relationship,” or just circled the disease. Although we were looking for circles around the types of diseases, the imprecision of the word *one(s)* led respondents to provide too much data or data that was not useful. As also occurs in question 6, there is no way for us to identify whether a respondent chose to not answer the question or negatively answered all parts of the question.

In another instance of imprecise language, question 7 uses *is* while referring to the increase in Lyme disease:

7. In Vermont, there has been a drastic increase in Lyme disease over the past 10 years.

- Were you aware of this increase? Y / N
- Why do you think this is?

The response rate to part two of this question could have potentially increased with the usage of more precise language (i.e. *What do you think is the cause of the increase?*). Several respondents commented verbally or on the survey that this was an unclear question. We never specifically reviewed the survey for such inappropriate cross-referencing, which manifested itself in such imprecise wording and could have contributed to respondent error and disengagement.

Appendix A.2: Suitability of Assessment of Materials index

FOR SURVEY

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Table 1. Suitability assessment of materials (SAM)*

Factor to be Rated	Score	Comments
	0 = Not Suitable 1 = Adequate 2 = Superior	
1. Content		
a. Purpose is evident	1	NO EXPLANATION
b. Content about behaviors	N/A	
c. Scope is limited	2	LIMITED TO VBD
d. Summary or review included	N/A	
2. Literacy Demand		
a. Reading grade level	1	FLESCH-KINCAID GRADE LEVEL: 6.6
b. Writing style, active voice	2	
c. Vocabulary with common words	2	RELEVANT
d. Context given first	2	
e. Learning aids via "road signs"	N/A	
3. Graphics		
a. Cover graphic showing purpose	N/A	
b. Type of graphics	N/A	
c. Relevance of illustrations	N/A	
d. List, tables, etc. explained	N/A	
e. Captions used for graphics	N/A	
4. Layout and Typography		
a. Layout easy to follow	1	
b. Typography appropriate	1	
c. Subheads ("chunking") used	N/A	
5. Learning Stimulation and Motivation		
a. Interaction used	N/A	
b. Behaviors modeled and specific	N/A	
c. Motivation / self-efficacy	N/A	
6. Cultural Appropriateness		
a. Match in logic, language, experience	N/A	
b. Cultural image and examples	N/A	
Total SAM Score: 12		
Total Possible Score: 16	75%	
Percent Score: % Not Suitable Material		SUPERIOR <i>(ROOM TO IMPROVE)</i>

Interpretation of SAM percentage ratings:

70 – 100% = superior material 40 – 69% = adequate material 0 – 39% = not suitable material

* The SAM tool was validated with 172 health care providers from several cultures, including Southwest Asians, Native Americans, and African Americans, as well as students and faculty from the University of North Carolina School of Public Health and Johns Hopkins School of Medicine. The SAM was developed under the Johns Hopkins School of Medicine project, "Nutrition Education in Urban African Americans," funded by the National Institutes of Health, National Heart, Lung and Blood Institute, Bethesda, MD, 1993.

Appendix A.3: Survey Respondent Demographics

Income	n=269
\$10,000 or less	12%
\$10,001-36,000	26%
\$36,001-90,000	35%
\$90,001 or more	16%
No answer	12%

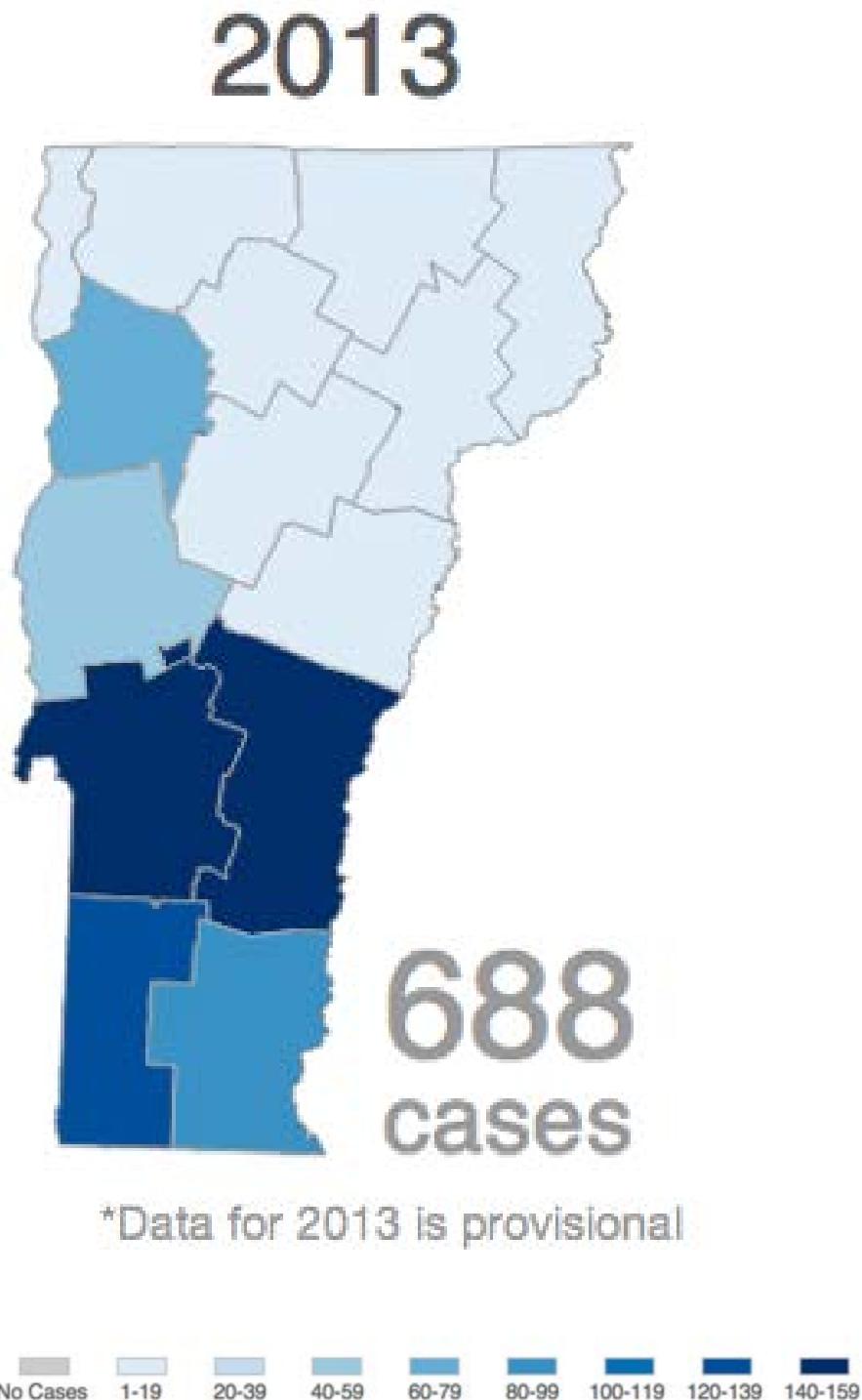
Age	n=269
18 and below	7%
19-40	20%
41-60	35%
61 and above	36%
No answer	2%

Gender	n=269
Female	65%
Male	32%
Other	>1%
No answer	3%

Appendix B: Verbal Survey Questions and Maps

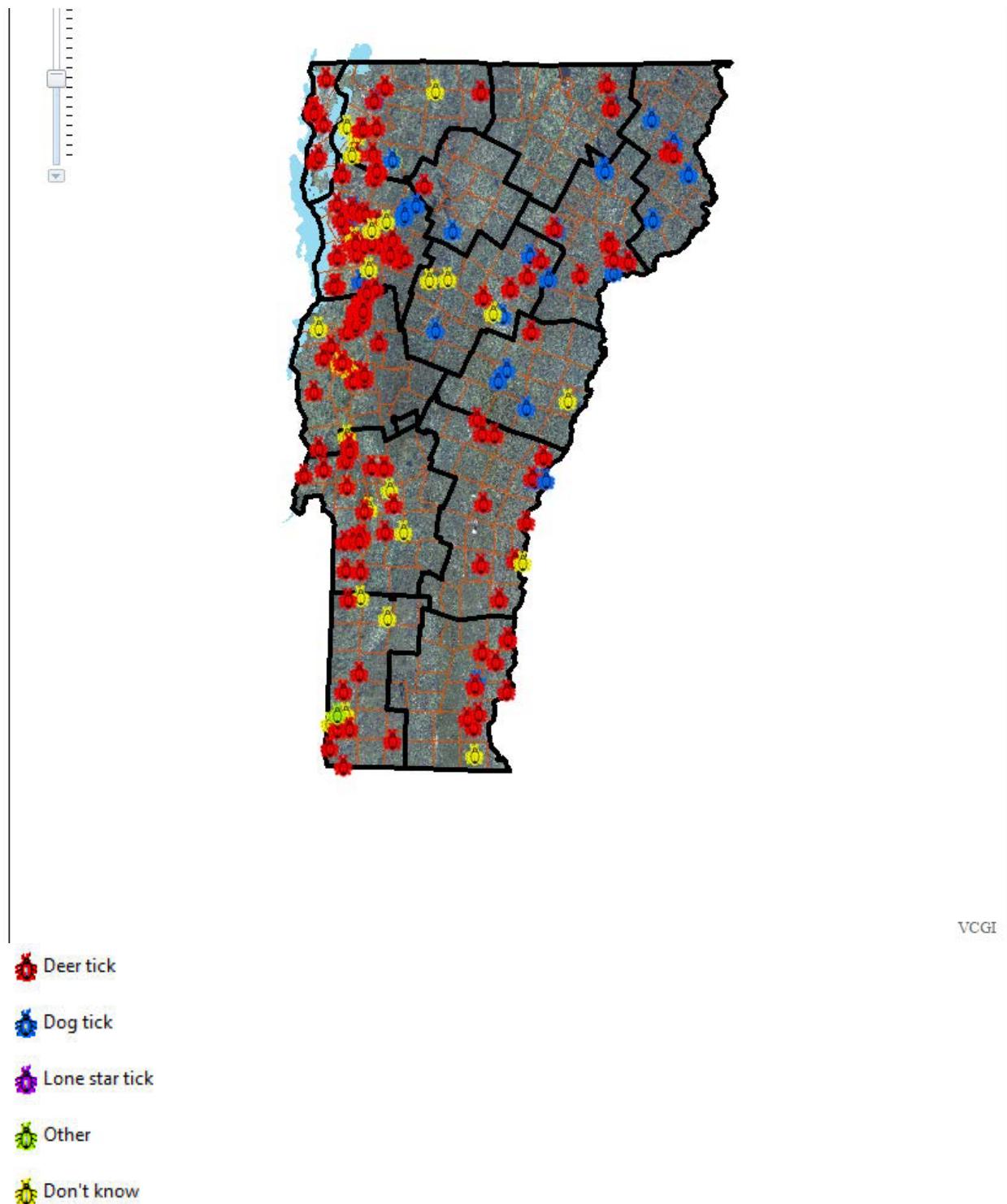
Which Map 1-4 makes you feel most at risk for Lyme Disease?
What features in this map communicate this risk?
Which Map 1-4 do you think communicates the data most clearly?
What features in this map did you like?
Which Map 1-4 did you find most helpful in assessing your personal risk for contracting Lyme disease?
What elements of the map were helpful?
In looking at Map 5, how does seeing the change in Lyme Disease over time impact your perception of risk?

Map 1: Probable Cases By County



Source: Vermont Public Radio (<http://www.vpr.net/apps/lyme-disease/>)

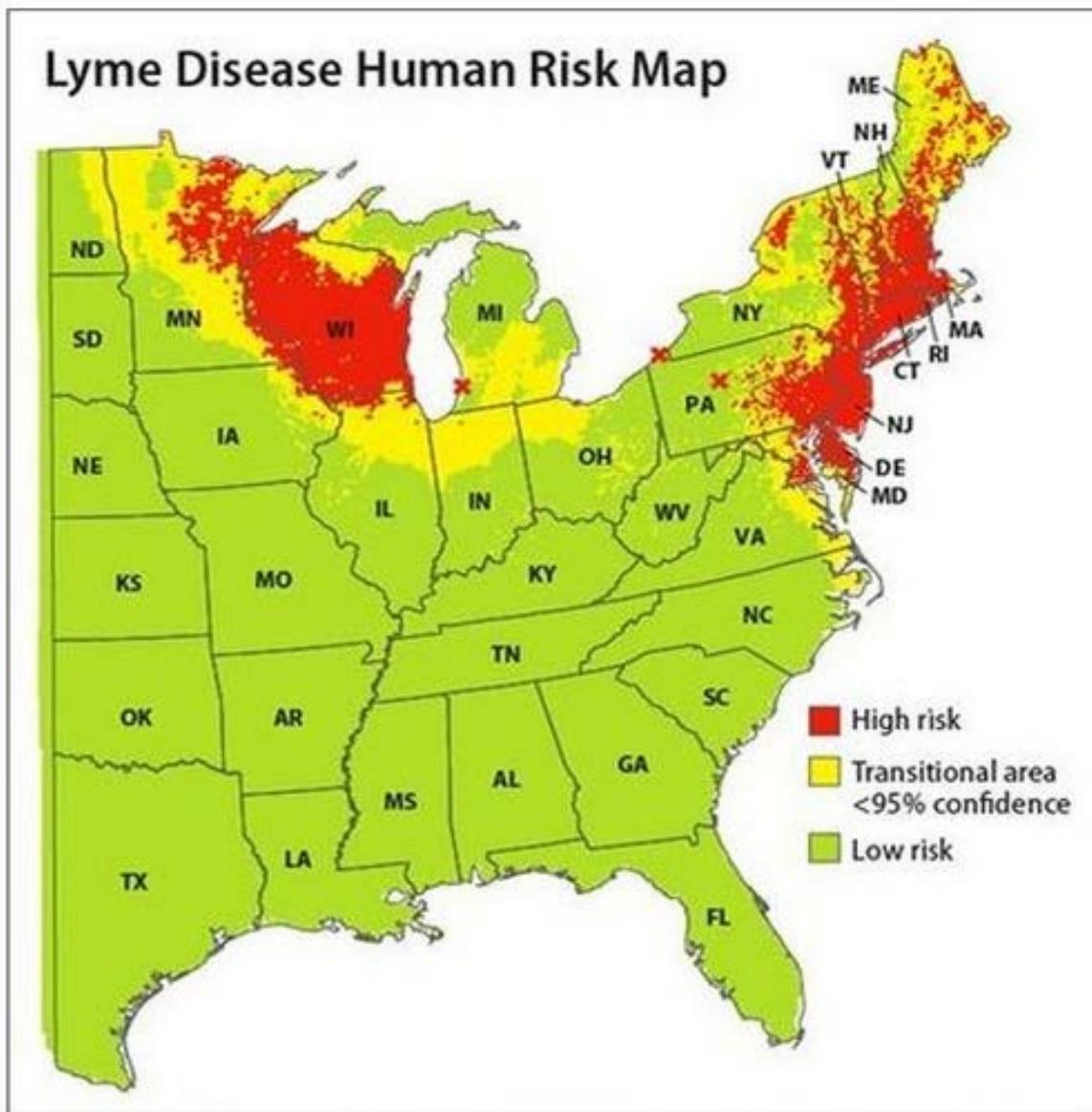
Map 2 : Vermont Tick Tracker 2013



*Deer ticks are the known vector for the bacteria that causes Lyme Disease

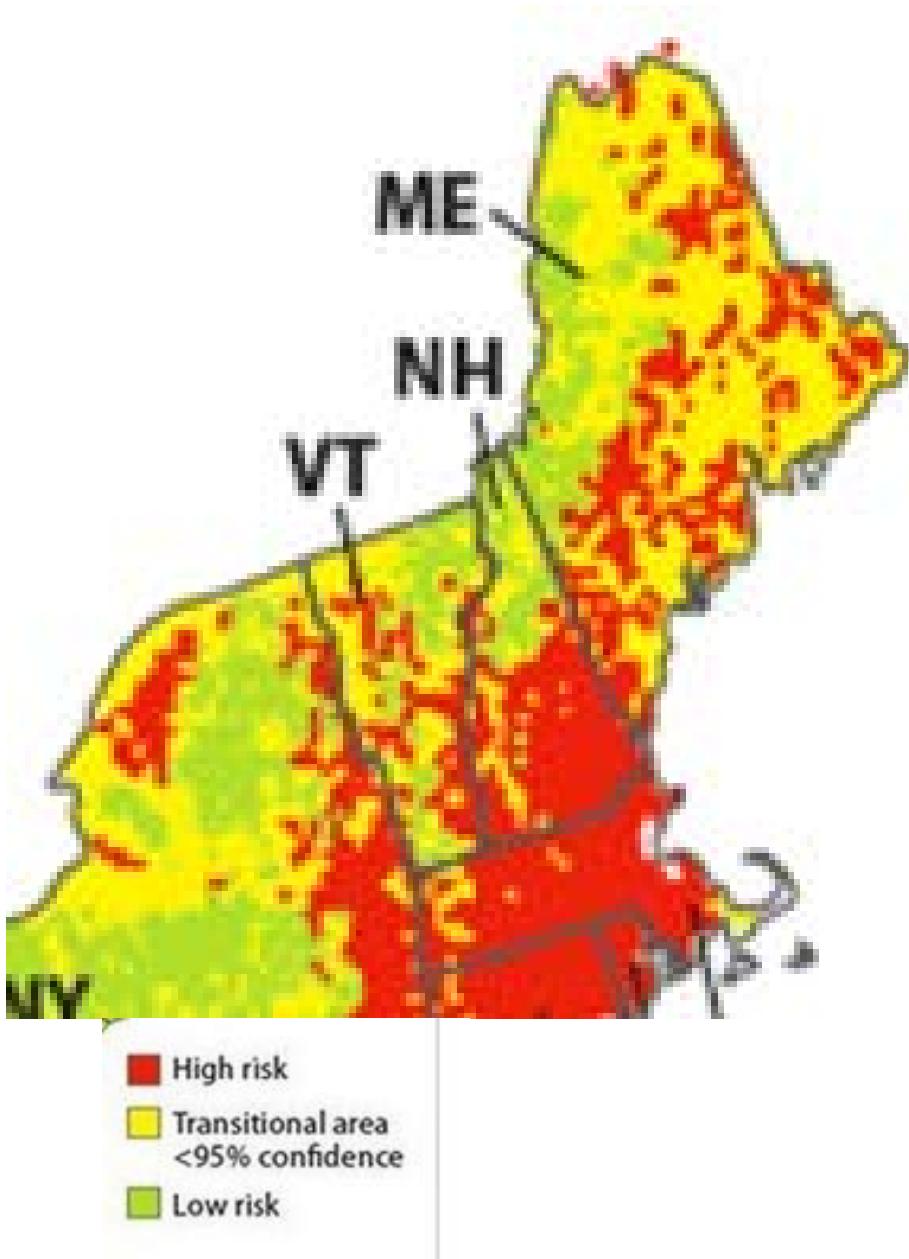
Source: Vermont Department of Health (<http://healthvermont.gov/ticktracker/>)

Map 3: Lyme Disease Human Risk Map (New England relative to US)



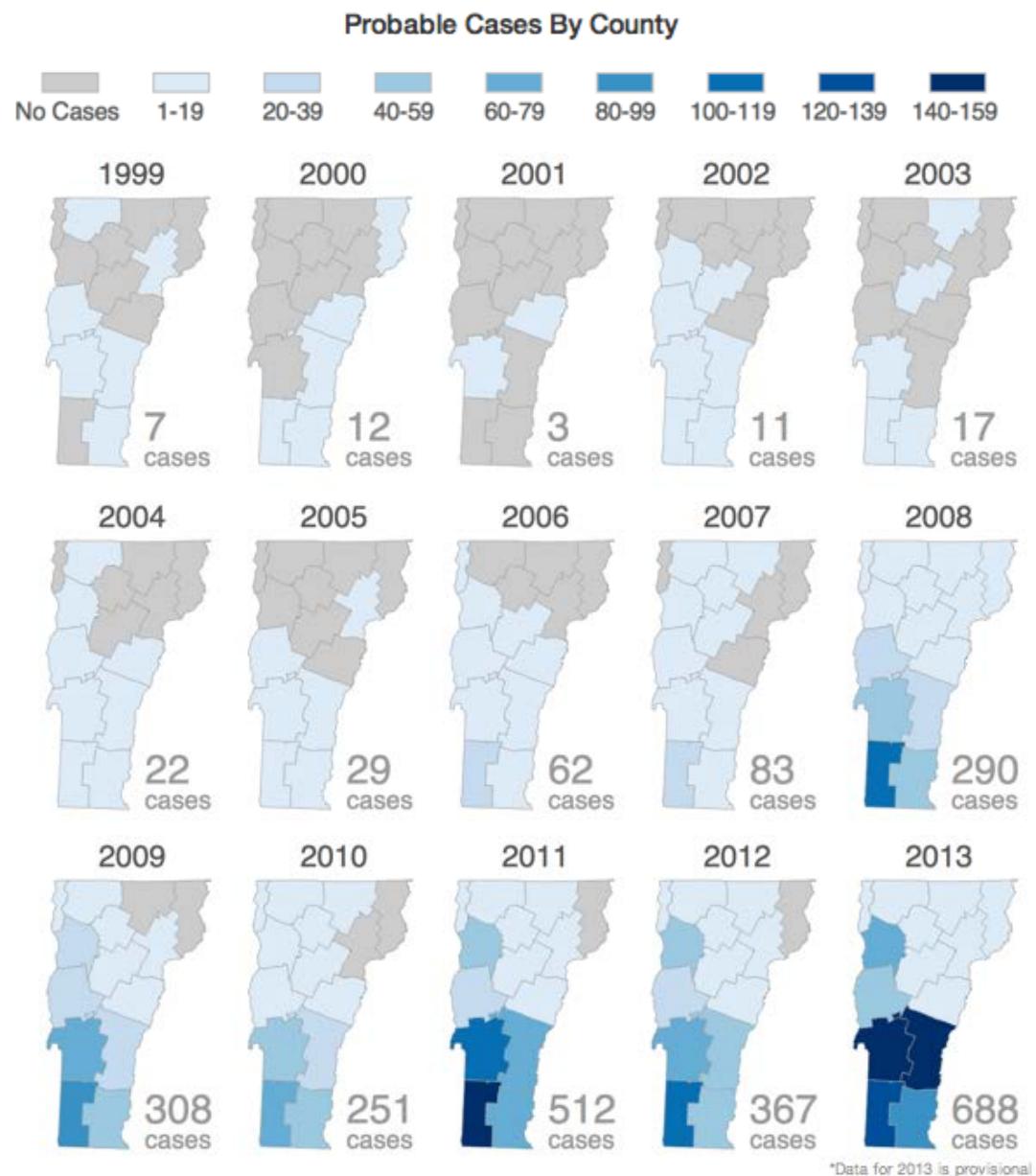
Source: Yale School of Public Health
<http://publichealth.yale.edu/emd/research/zoonosis/projects/tick.aspx>

Map 4: Lyme Disease Human Risk Map (zoomed to New England)



Source: Source: Yale School of Public Health and edited to create larger scale graphic (<http://publichealth.yale.edu/emd/research/zoonosis/projects/tick.aspx>)

Map 5: Change over Time



Source: Vermont Public Radio (<http://www.vpr.net/apps/lyme-disease/>)

Appendix C: Focus Group Materials

Lyme Disease and Chronic Illness: <https://www.youtube.com/watch?v=xYMezkigMWk>



Richard L. Horowitz, M.D. is a doctor from Hyde Park, New York. He believes that Lyme disease and other tick-borne diseases are something we should all be concerned about. The CDC recently released a report that Lyme disease is 10 times worse than previously suspected. Originally, it was reported that there were 30,000 cases of Lyme per year, but now they are reporting that it is actually 300,000. Dr. Horowitz believes the real number might actually be higher.

Ticks Take A Bigger Bite Out Of Vermont: https://www.youtube.com/watch?v=3dkwZ1QIy_4



Jon Turmel is an entomologist. He says that the two most common ticks in this area are the Black-legged tick, which spreads Lyme disease, and the Dog tick. Reports of Lyme disease have increased since 2006. Turmel explains several reasons for this increase: global warming, acclimatization of ticks, increases in the deer population, and proximity of deer and ticks to human populations. Considering this increased risk, Turmel recommends people spending time outdoors be diligent in checking for ticks and take other precautions to reduce their risk.

Lyme Research Alliance 2014 Gala Video - The Faces of Lyme:
<https://www.youtube.com/watch?v=ASytEK-TiE>



This is one of the many faces of Lyme disease patients. She describes the painful symptoms she experienced: "It felt like fireworks. It felt like something was... poking me with pins." She was a professional dancer, but when facing the symptoms of Lyme disease, she couldn't complete a normal 3-minute dance routine.

Focus Group Survey

1. Have you or someone close to you had Lyme disease?

Yes No

2. What is your chance of getting Lyme disease in the next year?

None Low Moderate High Very High I don't know

3. My risk for getting Lyme disease is: (circle one) Increasing Decreasing No Change

4. Which perspective did you find most persuasive about the risk of contracting Lyme disease?

Doctor Scientist Personal Narrative

Why was this perspective the most persuasive about the risk of contracting Lyme disease?

5. Which perspective did you find the most trustworthy in the information they were delivering?

Doctor Scientist Personal Narrative

Why was this perspective the most trustworthy?

6. Would you consider changing any behaviors to avoid getting Lyme disease?

Yes No

If yes, which ones?

Examples of answers provided for Question 6 on Focus Group Survey:

“Would you consider changing any behaviors to avoid getting Lyme disease? If yes, which ones?”

- “Full body checks right away after being outside. Showers right away. Socks over pants”
- “Full body checks after being outside”
- “Clothes 20 min in dryer on high settings after time spent outside”
- “When outside – high boots, pants in socks, long sleeve with tight cuff, shirt tucked into pants”
- “Spray the yard”
- “Checking pets for ticks”
- “Avoid tall grass areas”
- “Absolutely. Prevention/landscaping/travel+ activities at certain times of year, use of repellents/tick checks.”
- “Yes, I still go into the woods, however, I don’t go in during summer. I check myself afterwards + my dog. Pretty much daily checks.”
- “Light-colored pants with socks over bottoms”
- “Dress in light clothing, check after having spent time outside!”
- “Yes, talk to authority about all the laws against Lyme disease”
- “Never go in the woods any more. Check my body more often. Keep dogs close to house”
- “Tick checks, reduce outdoor exposure in endemic areas, moving to desert”
- “Body checks, avoid woods, be alert, consider moving”
- “Ultimately to prevent it, I could get rid of my dog + never go outdoors. I’m not really ready to go to that level.”
- “I already do everything I can to prevent a tick bite – clothing, DEET etc.

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